The perceptions of HIV Positive patients (ART patients) on ART and Treatment Supporters with regard to their role towards ART adherence, at ART clinics in the Intermediate Hospital Oshakati, Namibia.

Olivia Ningeninawa Tuhadeleni

Assignment presented in partial fulfilment of the requirements for the degree of Master of Philosophy (HIV/AIDS Management) at Stellenbosch University

Africa Centre for HIV/AIDS Management
Faculty of Economics and Management Sciences
Supervisor: Gary Eva
March 2011

Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: 5 March 2011

Abstract

This study sought to explore and describe the perceptions of ART patients, treatment supporters and health care workers about their roles in ART adherence as well as their perceptions about factors that affect ART adherence. This study was carried out at Oshakati ART clinic in the Intermediate Hospital Oshakati in Oshana region, Northern Namibia. A descriptive explanatory design was used. Unstructured interviews as data collection method was applied. The net positive pressure theory is used to analyze perceptions on roles and factors affecting ART adherence. Perceptions were sought from three groups namely ART patients, treatment supporters and health care workers.

The findings revealed that ART patients, treatment supporters and health care workers perceived their roles as pivots to ART adherence and all had positive perceptions. It also revealed that most of the participants were knowledgeable about the factors that affect ART adherence and economic factors as transport, money and poverty were among the most reported. ART clinic related factors such as staff negative attitudes and long queues were also reported as hindering adherence. Feeling better, use of alternative medication and religious beliefs were reported as having a negative effect on ART adherence. This study also revealed the importance of psychological and emotional support which was perceived as having a critical role in ART adherence.

Health care workers and treatment supporters perceived adherence as an important aspect in the success of antiretroviral treatment. Giving patients correct information, personal motivation, patients understanding of treatment, traditional and religious beliefs were among other factors perceived by health care workers to be impacting on ART adherence.

Opsomming

Hierdie studie het gepoog om persepsies oor anti-retrovirale behandeling (ARB) van pasiënte, behandeling ondersteuners en gesondheidswerkers oor hul rol in trou bly aan ARB asook hul persepsies oor faktore wat trou bly affekteer te ondersoek en beskryf. Die studie het by die Oshakati ARB Kliniek in die Oorgangshospitaal Oshakati in Oshana streek, Noord Namibia plaasgevind. 'n Beskrywende verklarende ontwerp is gebruik. Ongestruktureerde onderhoude is gebruik vir data insameling. Die 'net positive pressure' teorie is gebruik om die persepsies oor rolle en faktore wat ARB trou bly affekteer te analiseer. Persepsies van drie groepe, dws ARB pasiënte, behandeling ondersteuners en gesondheidswerkers is gesoek.

Die bevindinge het gewys dat ARB pasiënte, behandeling ondersteuners en gesondheidswerkers hul rolle gesien het as draaispille tot ARB trou bly en het almal positiewe persepsies gehad. Meeste van die deelnemers het kennis gehad oor faktore wat trou bly aan ARB affekteer, en ekonomiese faktore soos vervoer, geld en armoede was meeste aangemeld. ARB kliniek-verwante faktore soos negatiewe houdings van personeel en lang toue was ook genoem as hindernisse. Om beter te voel, die gebruik van alternatiewe medikasie en godsdienstige gelowe is genoem as kwessies wat negatiewe effekte op ARB trou bly het. Die studie het ook die belangrikheid van psigologiese en emosionele steun uitgelig, wat gesien was krities in hul rol in ARB trou bly.

Gesondheidswerkers en behandeling ondersteuners het trou bly gesien as 'n belangrike aspek van antiretrovirale behandeling. Die gee van korrekte inligting aan pasiënte, persoonlike motivering, pasiënte wat behandeling verstaan, tradisionele en godsdienstige geloof was ander faktore wat gesondheidswerkers gesien het as belangrik vir ARB trou bly.

Table of contents

Chapter 1: Introduction and orientation to the study

1.1 Introduction

This chapter introduces the orientation to the study in which the formulation of the background of the problem, research problem, knowledge gap, research question, justification, aim and objectives are described.

Namibia is one of the countries in Sub Saharan Africa, the region most affected by HIV and AIDS (UNAIDS 2007). The anecdotal reports among the community about patients defaulting from ART programmes brought a concern about the patients' adherence to life long ART regimens. By the end of 2005, about 14,400 patients were enrolled on ART programme in various public health facilities. In the 2008/2009 financial year, about 10 009 HIV positive patients were registered for ART at ART clinic in the Intermediate Hospital Oshakati, about 17% defaulted from ART programme in the financial year 2008/09.

1.2 Background of the problem

HIV/AIDS is a global problem in the world. According to UNAIDS and WHO report of December 2007, 33,2 million people are living with the HIV/AIDS globally. The region most affected is Sub-Saharan Africa which has approximately 25 million HIV infected people. Namibia is one of the five countries mostly affected by the world pandemic (UNAIDS and WHO, 2007).

In Namibia, the national HIV/AIDS prevalence rate of 2008 is estimated 17,8% with a 21% rate for Oshana region. According to Health Information System for Oshana region, 2008/2009, approximately 10 009 HIV positive patients were registered for antiretroviral therapy of out of which about 17% defaulted. This means that 17% represent poor ART adherence (MOHSS, Health information report: 2009).

Oshana region is one of the 13 of regions in Namibia, in the northern part of the country. The population of the Oshana region was estimated to be 183 452 for 2009. Namibia's population is approximately 1.8 million (National Census, 2002). HIV/AIDS is a common

health problem, defaulters of antiretroviral treatment become a weekly problem in Oshana region, and it is against this background that the researcher intended to look at the perceptions of HIV positive patients on ART, and treatment supporters about their roles related to ART adherence. Medicine adherence refers to the instructions of doctor's prescriptions concerning a certain medicine, to take the right medicine, right dose at a right time, and come to follow ups as scheduled.

Though the first case of HIV/AIDS in Namibia was reported in 1986, antiretroviral treatment (ART) was only introduced in 2003. In 2004, the ART was piloted in 4 regions and in 2006 the service was rolled out to all districts and regional hospitals in the country in order to make the service accessible to those who need them. Currently all three (3) intermediate hospitals, 34 district hospitals and 84 health centers provide ART services in Namibia. According to the ART guideline 2007, the first line treatment is Zidovudine (AZT), Stavudine (D4T), Lamivudine (3TC), Nevirapine (NVP) and Efivarence while the second line treatment is Fumarate (TDF) Lamivudine (3TC) Lopinavir (LPV), Didanosine (ddi) and Abacavir (ABC) (MoHSS, 2007, p7). Poor adherence makes patients to fail first line of treatment and this makes them to be put on the second line of treatment with is more expensive and complicated side effects (MoHSS, 2007).

According to the national guideline for ART (MoHSS 2007), the adolescents and adults should meet World Health Organization criteria of clinical stage 3 and 4 of HIV disease, irrespective of CD4 cell count. A patient will be eligible to ART when he or she has a CD4 cell count of ≤ 200 cell/mm^3 and ≤ 250 cell/mm^3 for pregnant women (MoHSS, 2007, p3).

According to the Ministry of Health and Social Services' ART training guideline manual for health workers, 2009, ART adherence is when a patient takes his/her medication and obeys follow up medical visits according to the doctor's prescription schedule. The importance of adherence to ART treatment is that it helps the medicine to work effectively by suppressing the viral load and boosting the immune system of patients. The illnesses and deaths related to HIV/AIDS reduction is simply because CD4 cell counts increase and viral loads decrease. ART medicine adherence is vital for the success of Highly Active

Antiretroviral Drugs, and very high levels of attendance, taking at least 95% of prescribed doses, is required to sustain suppression of HIV growth (MOHSS, 2007).

Resistance of viruses to ART refers to a change in the virus that makes the virus protected and antiretroviral medicine ineffective. When the medicines are taken correctly without omission then the virus cannot multiply and make new copies (MOHSS, 2008, p50).

Other barriers are poor communication between patients and health care providers. With discomfort in disclosing HIV status, patients will not get support from families, friends or by HIV/AIDS support groups in their communities. Substance abuse may dilute the effects of ART medicine, or one may forget to take the medicine, or confuse the time when to take the medicine as well as the dose.

1.3 Different ways are used to improve adherence

Counseling services are done with patients and treatment supporters on the first visit and on every follow up at the clinic. Pre-ART initiation training sessions are carried out three times before initiation of ART. Support groups such as expert patients (patients living with HIV/AIDS) are available at the health centres; HIV/AIDS support groups are available in all 13 regions including Oshana region.

Networking is established between treatment supporters, community groups, health workers i.e. pharmacists, doctors, nurses and expert patients help to maintain ART adherence.

Joint planning for ART management is done every year to reach the common goal of 100% ART adherence. ART treatments are combined and being simplified. Despite this, patients found defaulting which was experienced among patients on ART, shows poor ART adherence in Oshana region.

1.4. Research problem

The clinical team supports patients by counseling and educating them about ART adherence and the benefits thereof.

The staffs that do not have experience in working with ART regimens and HIV patients on ART show negative attitudes, may not work accurately and not give relevant information concerning ART adherence.

There are no funds available to help patients on ART financially, with transport money, as some travel long distances of up to 60km to reach the nearest health facility. Some patients experience household food insufficiency due to recurrent natural disasters i.e. flood in 2008 and 2009 which destroyed their crops.

Self stigmatization among HIV positive patients on ART occurs, and sometimes they are stigmatized by the health workers or by their community members.

The lack of public transport especially to the patients living in the remote areas results in defaulting. Some patients may have irregular attendance due to lack of public transport, lack of transport money or lack of family support where there is no one to accompany her/him to the clinic. Psychological problems e.g. stress, psychosis, or exhaustion can make some patients not to attend their follow up regularly.

1.5. Knowledge gap

The role of HIV positive patients on ART and the treatment supporters on ART adherence is not well understood**.**

1.6. Research question

What are the perceptions of HIV positive patients, the treatment supporters, and also health care workers regarding their expected roles on ART adherence?

1.7. Significance of the study

It is useful to conduct such a research study as it will help to gain an understanding of the perceptions of HIV positive patients on ART, the treatment supporters, as well as health care workers regarding their role towards ART adherence. The findings will assist the researcher to make appropriate recommendations to the relevant authority, who will make

sure that the recommendations are implemented. The implementation of the recommendations of this study will provide the improvement of adherence interventions in future. There may, ideally, be a reduction in HIV/AIDS related death rate, less social cost, improved ability to work and in return it can contribute to social development.

1.8. The Aim

The aim was to gain the insight and the understanding of the HIV positive patients on ART and the treatment supporters regarding their role in ART adherence. The research findings can inform the health workers about better ART management strategies such as better counseling and education of HIV positive patients and treatment supporters regarding ART adherence. The research findings may also help in developing a guideline of HIV positive patients and treatment supporters as well as health care workers about the role they should play in ART adherence, in order to improve adherence to antiretroviral therapy.

1.9. Objectives

1. To explore perceptions of patients on ART treatment supporters and health care workers about:
    a) their current roles in ART adherence, and
    b) factors that can influence adherence.
2. To determine the knowledge gap of patients on ART, treatment supporters and health care workers towards ART adherence.

Chapter 2: Literature Review

2.1 Introduction

The purpose of a literature review is to provide better insight into dimensions of the research problem. A literature review further equips the researcher with justification for the subsequent steps to be followed in the research process. Gaps in some previous research were identified and discussed. The literature review aims at refining and redefining the research questions as well (De-Voss & Fouche 2001: 66-67).

The research topic and related aspects are studied in depth and discussed in chapter five. The concept of adherence, measurement of adherence, roles of ART patients, treatment supporters, and health care workers (HCWs) in ART adherence, as well as their perceptions of factors affecting ART adherence are discussed in this study.

The net positive pressure theory (designed by the researcher) is used as the theoretical framework to describe and analyze the research issues. The relevance and the application of the theory will be discussed in the study.

2.2. Adherence

Machtinger and Bangsberg (2005:3) define medication adherence as the extent to which a patient takes medication in the way intended by a health care provider. In a study done by Weiser et al (2005:282), adherence in relation to ART is defined in the following terms: taking 95% of prescribed doses over the previous year which is equivalent to missing not more than one dose in a ten day period. Other data suggest 100% adherence to achieve greater benefit for ART (clinical manual 2005:2). According to Nieuwkerk, Spranger; Kauffmanm, Janbroes, Chesney, De Wolf and Lange (2001:196), adherence to ART includes taking multiple drugs two to four times a day according to a strict schedule. For the purposes of this study, adherence means that patients follow the prescribed antiretroviral treatment regimes in accordance with time and dietary requirements. Adherence to medication is crucial for effective therapy. Unfortunately lifelong adherence to such levels is not very easy in Namibia and Southern Africa as a whole (Machtinger & Bangsberg

2005:2-3). Despite the fact that long-term viral suppression requires near perfect adherence, the average rate of adherence to ART is approximately 70% worldwide (clinical manual 2005:2). According to Machtinger and Bangsberg (2005:3), non adherence to ART is common in all groups of treated individuals. Lack of strict adherence to ART is considered one of the key challenges to AIDS care worldwide (Weiser et al 2003:281). In Oshana region, Northern Namibia, no related study has been conducted. This indicates that little attention is given to evidence based on ART management.

A study done in Botswana on barriers to ART adherence for patients living with HIV infection and AIDS revealed that the majority of patients found it difficult to achieve 95% adherence (Weiser et al 2003:284). The study was a cross-sectional study of the social, cultural and structural determinants of treatment adherence. Level of adherence of people receiving ART in three private clinics in Botswana between January and July 2000 were reported. The patients were asked to indicate their adherence over the previous day, previous week, previous month and previous year. Adult patients who had been receiving ART for at least three months were eligible. Health care providers (that is the physicians, nurses and pharmacists) were asked to indicate their assessment of the patient's adherence over the previous year. Adherence was defined as taking 95% of prescribed doses over the past year. The findings were that 54% of patients were adherent with more than 95% of prescribed doses.

The central role of adherence to ART is to ensure successful treatment of HIV, and that has prompted a flurry of research into adherence and increased physicians interests in an attempt to address issues in the context of ongoing care (Turner 2002:5149). The following section discusses the importance and measurement of adherence.

2.2.1 The importance of adherence

Adherence, toxicity, and resistance are matters of intense research, which need to improve in order to overcome the current limitations of available drugs (Cahn, 2004:55). According to Simpson, Whipper-Lewis, Mazyck (Sa) (downloaded 04/03/2011), adherence to ART is essential to both primary and secondary prevention in HIV related disease. Adherence to

ART results in a decrease in viral load, morbidity and mortality. Adherence to ART improves survival, decreases hospitalization and acute illness and decreases the transmission risk 10 to 100 fold. Proper adherence also results in minimizing the emergence of drug resistant strains and an increase in CD4 lymphocyte count as discussed below. Drug resistance is a burning issue that in turns to threaten the gains of ART treatment.

2.2.1.1 Drug resistance

One of the biggest problems associated with ART in Africa is the emergence of resistance strains. Adherence remains a worldwide challenge to the success of ART especially with the emergence of drug resistant strains. Sub-optimal adherence facilitates the emergence of drug resistance HIV-1 variants. Drug resistance strains are transmissible and that is why non-adherence becomes a public health concern. The problem of resistant strains can result in resistant viral strains of HIV being transmitted to newly infected individuals who will therefore have fewer treatment options from the onset (Kgatlwane, Ogeny, Ekezie, & Mdaki 2008:7).

Vardavas and Blower (2005:2) did a study on the emergence of drug resistant HIV strains in Botswana. The study aimed at predicting the evolution of drug-resistant strains of HIV that may emerge as a consequence of ART. A mathematical model was used to predict the temporal dynamics of transmitted resistance up to 2009. The results showed that if drug resistant stains that evolve were only 25% as transmissible as the existing strains, then transmitted resistance would reach at most just below 3% by 2009. If drug resistant strains that evolve are 50% as transmissible as the current strains then drug resistant strains will reach 6% by 2009. Levels of transmitted resistant strains are predicted to reach 13% by 2009. If the drug resistant strains are as transmissible as the existing strains, higher results are expected if the drug resistant strains that evolve are more transmissible than existing strains.

Currently, relatively little is known about the transmissibility of drug resistant strains of HIV in vivo (Vardavas & Blower 2005:4). In the United States, the average adherence rate to ART is 70% and this poses the risk of drug resistance (clinical manual 2005:2).

Adherence is therefore a very important area of research in the context of emerging drug resistance.

2.2.1.2 Viral load and drug levels

The significance of adherence is emphasized in the study by Nieuwkerk et al (2001:1961). This study was conducted in the Netherlands, between 1998 and 1999 and involved HIV infected patients who were 18 years and above. The patients were enrolled in an observational cohort study. Patients who reported deviation from the regimen showed lower drug exposure compared to fully adherent patients. Among those receiving ART for at least 24 weeks, patients reporting deviation from their regimen were less likely to have plasma HIV-RNA levels below 500 copies/ml compared to fully adherent patients. Patients who reported taking all their medications not according to time and dietary proportions as prescribed were more likely to have a viral load above 500 copies/ml. The results indicate that poor adherence results in lower drug levels and higher viral load.

A similar conclusion was obtained in a study done by Isabelle, Mounirou, Alice, Karim, Fatou, Barra, Omar, Eric and Ibrahima (2003:5103-5108) in Senegal. The study assessed adherence and identified the main reasons for treatment interruption in a prospective observational cohort of patients participating in an antiretroviral access programme in Dakar, Senegal between November 1999 and October 2001. The relationship between adherence and virologic efficacy was also established, comparison of the mean viral load values was done between those with stated adherence of 90% or more and those with poorer adherence, which is below 90%.

Viral load was higher in the less adherent patients. Those results show the importance of addressing the issues of adherence for viral suppression in patients on ART. Kgatlwane et al (2005:7) reiterate that the viral suppressing effect of ART requires strict adherence to prescribed schedules.

2.2.1.3 Adherence and hospitalization

In a study done in Pittsburgh, USA, Paterson et al (2000:20) also reported the importance of adherence. In their study, patients with treatment adherence of 96% or greater had fewer hospitalization days than those with lower treatment adherence rates. In addition, no opportunistic infections or deaths occurred in patients who had an adherence rate of 95% or greater.

2.2.1.4 Disease progression and CD4 lymphocyte count

In a study investigating the relationship between level of adherence and risk of progression to AIDS, Bangsberg et al (2001:1182) found a strong relationship between the level of adherence to ART and the risk of progression to AIDS. Disease progression was defined as a decline in CD4 cell count to below 200 cells/ml or the development of opportunistic infections during follow-up. In the same study (Bangsberg et al 2001: 1182) using a population based cohort of HIV positive urban adults with high risk of non-adherence in San Francisco, it was found that none of those in the high adherence group developed an AIDS event during observations compared with 8% of those in the moderate adherence group and 41% in the low adherence group. A fall in viral load is associated with a steady rise in CD4 cell count (Anabwani & Jimbo 2005:3). The results from the study by Bangsberg et al (2001b:1182) showed the important of adherence in slowing down the rapid progression to AIDS by maintaining a low viral load and a high CD4 count.

Harriers et al (2001:410) emphasize the aspect of adherence as a significant barrier to delivery of ART therapy in sub-Saharan Africa. Proper adherence has been shown to improve life expectancy and prevents the spread of drug resistant strains. Studies that attempt to predict causes of non-adherence and studies that explore strategies that can reduce the number of missed doses continue (Castro 2005:4). Patients tend to trust health care workers and treatment supporters as sources of health information and advice (Hogan & Palmer 2005:9). Health care workers and treatment supporters are therefore well positioned to promote adherence because of the patient-provider relationships. Studying health care workers, treatment supporters and ART patients' perceptions of their roles in

ART adherence might offer useful insights into causes of non adherence and possible appropriate strategies that can improve non-adherence and foster proper adherence.

2.2.2 Measurement of ART adherence

ART treatment is a lifelong endeavor. However, pill fatigue usually sets in and patients who start off adequately adhering to therapy default at one moment or the other during treatment. Strategies that can assist patients who falter on their ART treatment and that strategy that helps to monitor and evaluate antiretroviral programmes and treatment outcomes need to be put in place if the fight against HIV/AIDS is to be won.

Although there are a variety of methods that can be used to measure treatment adherence, no single method is perfect (Machtinger & Bangsberg 2005:16). Each measure has its own merit and demerits. Turner (2002:51430), states that measurement of adherence may include patients' self-report, pharmacy-based approaches, pill counts and electronic monitoring.

2.2.2.1 Self-reports

Self-reporting is when the patient gives a drug history regarding missed or incorrect doses (Anabwani & Jimbo 2005:2). According to Turner (2002:5145), estimates of treatment adherence from patients self-reports are less complex to obtain than other methods. The advantages of self-reports are their low costs and flexibility of design. Questionnaires are easily collected and can help determine why patients are non adherent. The major limitation of self-reports is that they are subjective and reflect only short term or average adherence and may often exaggerate adherence.

In order to increase validity of self-reported adherence, it is important to present a preamble that reassures patients that information will not be held against them and that problems with adherence are not different but they are nearly universal (Turner 2002:5146).

2.2.2.2 Pill count

Pill counts involve counting of the remaining doses of medication in a specified cycle. The return of excess pills provides tangible evidence of non-adherence (Machtinger & Bangsberg 2006:16).

The health care provider or pharmacist can do pill counts, but the problem with this method is that it is time consuming, and determining the date when the patient commenced the current prescriptions can be difficult especially when patients combine all their pills in one bottle (Turner 2002:5146). Another problem identified is that patients dump pills in order to appear more adherent when counts occur. Unannounced pill counts were developed to counter this practice, and involve counting pills by health care workers at unannounced home visits. The problem with unannounced pill counts in that they are intrusive and cumbersome for common clinical practice (Machtinger & Bangsberg 2005:16).

2.2.2.3 Biological markers

According to Machtinger and Bangsberg (2005:16) biological markers of adherence are plasma concentration of antiretroviral drugs. According to authors, the problem with this method is that it can only detect recent adherence behavior. In addition, these tasks are often expensive and generally unavailable (Machtinger & Bangsberg 2005:16-17). This method is rarely used in Africa.

2.2.2.4 Pharmacy refill data

Pharmacy refill data can serve as an adherence measure by providing the dates on which antiretroviral medications were dispensed (Machtinger & Bangsberg 2005:17). Poor adherence is noted when there are no timely refills of medications. This method provides a less intrusive means of measuring adherence than most other measures (Machtinger & Bangsberg 2005:17).

2.2.2.5 Electronic monitoring devices

Micro electronic monitoring system (MEMS) is an electronic device that can be used to monitor adherence. These devices are pill bottles with caps that have an electronics chip

that records the number of times the bottle is opened. Researchers or health care workers can then download the data periodically from the chip and identify patterns of adherence (Turner 2002:5151).

Some studies have shown the sensitivity for MEMS to be very high for detecting non-adherence. In a study done by Arnsten, Damas, Farzadegam, Grant, Gourevita, Chano, Buono, Eckholdt, Howard and Schoenbaum (2001:1417-1423), MEMS was compared with self-reported adherence in an on-going cohort of drug users in New York in 1985. Although MEMS was found to be a more sensitive measure of clinically significant non-adherence it has its limitations. The system can only assess one prescribed medication, and in addition cannot generally measure adherence to other components of the combination therapy. The number of pills withdrawn at each bottle opening is not recorded (Machtinger & Bangsberg 2005:16).

2.2.2.6 Measurement of adherence in Namibia

The ART guidelines in Namibia recommend three or more of the following methods for measuring adherence.

(a) A careful drug history regarding missed or incorrect doses (self-reporting).
(b) Directly observed therapy by nurse, pharmacist, family member or friend (treatment supporters).
(c) Pill count (patients asked to bring back all remaining medication).
(d) Blood drug level measurements whenever available
(e) Periodic viral load and CD4 cell determinations.

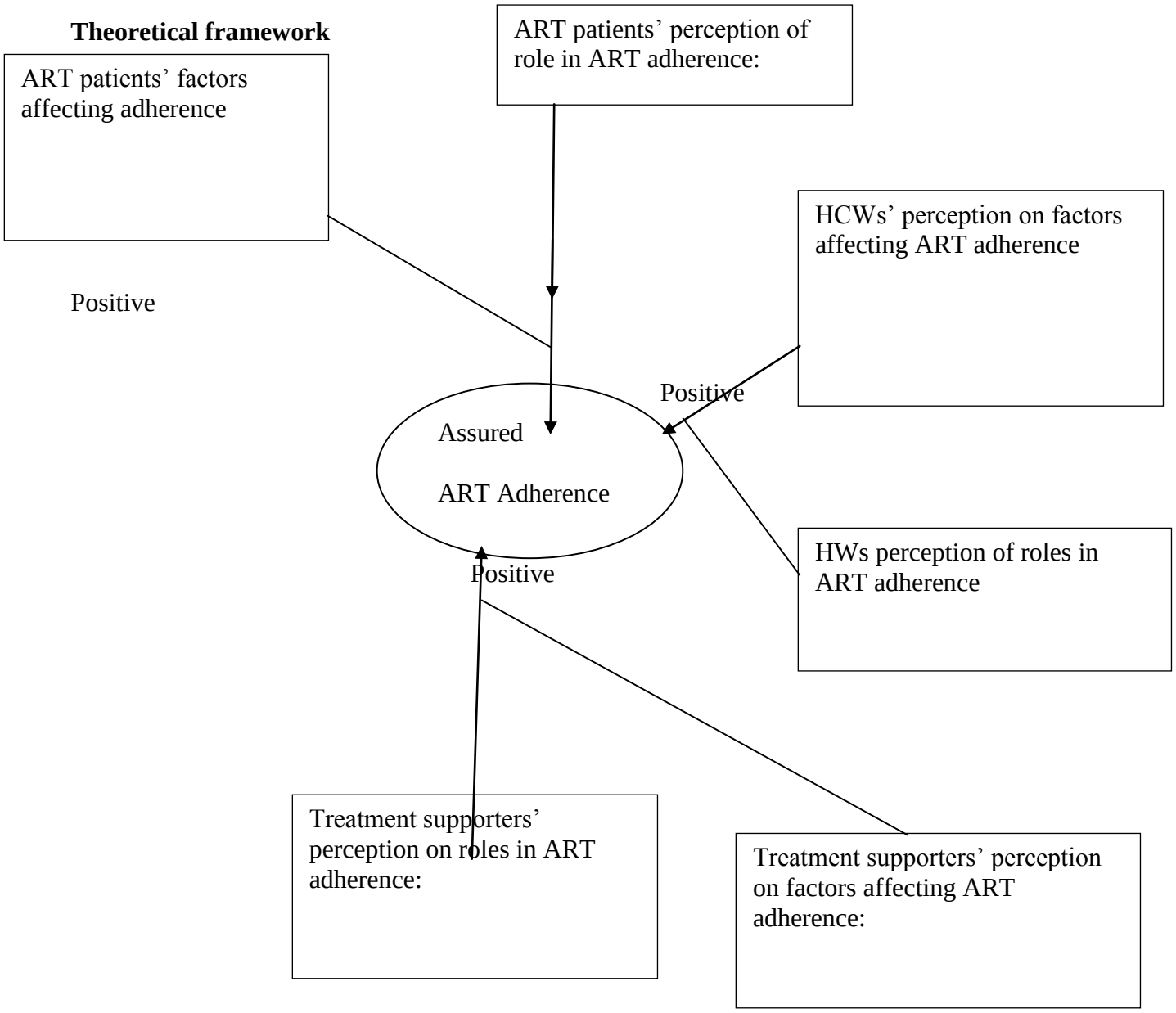
Clinicians are encouraged to assess adherence to ART at every routine visit (Anabwani & Jimbo 2005:6). In addition they are advised to use language that patients can understand. Discordance between the patients and doctors on adherence to drugs is often observed. Discordance is when there is a difference in the patient’s adherence rate as perceived and measured by the health care workers compared to patients' perceived adherence rate. Most patients perceive themselves as adherent while health care workers perceive more patients as non adherent. A study done in 2000 in Italy by Murri, Ammassari, Trotta, De Luca,

Melzi, Muriardi, Zaccarelli, Rellecati, Santapadre, Soscia, Scasso, Tozzi, Ciardi, Orofino, Noto, Monforte, Antinori and Wu (2004:11080) aimed at evaluating the rate of discordance between patients and health care workers on adherence to ART.

The results showed that health care workers were more often discordant with patients when they rated patients as adherent, than when they rated patients as non-adherent. So from the health care workers perspective, more patients were non-adherent. This discordance in the results was explained in part by inadequate communication between health care workers and patients. Similarly in a study by Weiser et al (003:285), there was some disagreement about which patients were able to adhere to treatment from the patients' self reports and the health care workers assessment. The observed amount of agreement between patients and health care workers was 68%. So, for health care workers to be able to accurately assess their patients' adherence, it is important to develop collaborative and non-judgmental relationship with patients (Machtinger & Bangsberg 2005:19).

2.3 Theoretical framework

Theoretical framework



Adopted from S. Chikukwa, 2009

Lecture notes on Theoretical framework (UNAM unpublished data)

The theoretical framework used in this research was adapted from the Net positive perceived pressure model. This model was developed by Chikukwa (UNAM 2009) (unpublished). The model has been used as a framework to develop the research objectives

and the research questions of this study. The literature review is also based on this model. The model was also used to guide the development of data collection instruments, the research findings and the conclusions.

The Net positive perceived pressure model is applicable to health behavior change. The positive perceived pressure model is an appropriate theoretical framework to use in the exploration of the final behavior of patients adherence to antiretroviral treatment. The model can also be applied to determine behavior of health care workers as well as treatment supporters in ART adherence.

ART patients' negative perceptions of their role in ART adherence as well as their negative perceptions on factors affecting adherence has a net negative effect on their final behavior on ART adherence which is this particular case will be more tilted towards non adherence. If however ART patients' perceptions of their roles in ART adherence are positive and they are as positive in their perceptions of factors affecting adherence then they will have a Net positive perceived pressure which is likely to make them more adherent. A combination of positive and negative perceptions by ART patients of their roles in ART adherence and factors affecting ART adherence will also have either a Net negative perceived pressure or a Net positive perceived pressure on ART adherence.

Treatment supporters' perceptions of their roles in ART adherence and their perceptions of factors, affecting adherence will also yield a net perceived pressure on their patients' final adherence outcome. If their net perceived pressure is positive then their patients are more likely to adhere, but if negative then their patients are likely to be non-adherent. This also applies to the health care workers.

2.4 Role perceptions of ART patients, treatment supporters and health care workers

The patient is regarded as an equal player in ART adherence. The main responsibility of the patient is to understand the HIV/AIDS disease fully; then understand ART treatment including the importance of medication and adherence. The patient is then expected to appoint a treatment supporter who will support him/her psychosocially and emotionally.

The patient will then have the responsibility to go for follow up visits, and collect mediation. It is also the responsibility of the patient to disclose their status to family and friends and gain support from them. The patient is expected to be seen taking medication daily and at the same time with food. The patients must always report to a health facility early in case they are not feeling well or they notice any side effects.

On the other hand health care workers are supposed to provide a user friendly atmosphere for patients by demonstrating empathy and professionalism. Health care workers must impart information through continuous counseling of patients, and must discuss treatment regimens with patients as well as educating them on side effects.

Health care workers must prescribe medication and dispense it to ART patients. Health care workers must monitor patients for adherence either by pill count, patient self reports, or patient appointments. The health care workers must change medication when side effects are noted or must manage the side effects.

Treatment supporters must offer psychosocial and emotional support to their patients. They must make sure they know much about ART treatment and clarify some of the myths and misconceptions of ART treatment. They must help health care workers reinforce positive behavior among their patients and maximize ART adherence. Treatment supporters must also help patients by reminding them of their medication as well as taking their patients to ART clinic for follow ups and collection of medication.

2.5 Perceived factors affecting adherence

Adherence to ART can be improved by identifying the barriers to adherence and factors that facilitate adherence. Therefore, identifying and overcoming the factors that reduce uptake of antiretroviral agents is of utmost importance for prolonged viral load suppression. Health care workers, ART patients and treatment supporters' understanding of factors affecting adherence and his/her perception of how these factors impact on the individual patient will determine intervention strategies that they will use to modify patient’s behavior of adherence to ART. Weiser et al (2003:286) are of the opinion that identifying barriers is

critical if policy makers in African countries are to identify pitfalls in current treatment strategies and if they are to devise effective AIDS treatment programmes.

From the literature reviewed in this study, the factors perceived to affect patient's adherence to ART include cost, geographical factors, nature of treatment regimens, health care worker factors, social habits and lifestyle and stigmatization, socio-demographic factors, and migration. Some of these factors are discussed below.

2.5.1 Cost factors

The net positive perceived effect model hypothesizes financial costs as an influence on a patients' ability to change and maintain adherence to ART. The patients' contribution to their treatment costs might have a positive or negative impact on adherence. In developing countries high costs of antiretroviral treatment remain a barrier to effective treatment and have negative implications on ART adherence. That high costs are a challenge to the treatment of HIV/AIDS in developing countries has been confirmed by a study done by Isabelle et al (2002:5103-5108) in Senegal. The study, which aimed to assess adherence and causes of treatment interruption among patients, recruited from 1999-2001. Some patients were treated free of charge, while another cohort of patients contributed towards the cost of their treatment. One of the findings was that the mean adherence among patients decreased as their financial participation increased.

In Namibia ART treatment is now free. The challenges of costs still haunt the patients due to transport, and food related costs. Non monetary costs as time off from income generating activities are some of the net negative perceived effects of factors affecting adherence. In a study done in Botswana costs and financial constraints were found to be significant barriers to treatment. Seventy percent (70%) of potential participants mentioned cost as a problem. Fifty five (55%) percent of patients stated that their overall economic situations interfered with their ability to take treatment. About fifty six percent (56%) of health care providers believed that financial problems often or always impeded adherence to ART. Patients on ART were receiving suboptimal regimens and underwent forced treatment interruptions due to these financial constrains (Weiser et al 2003:282). On the basis of logistic regression, if

cost were removed as barrier, adherence was predicted to increase from 54% to 74%. Though cost may be a hindrance in ART adherence, perceived benefits may outweigh perceived financial strains and patients may go out of their way to ensure they overcome financial constraints and receive their treatment.

2.5.2 Geographical factors

The net positive perceived effect model addresses distance as a probable force that can impact negatively on patient's adherence behavior and outcome. Weiser et al (2003:285), cited that some reasons cited as difficulties for patients to adhere to ART treatment included the need to be absent from work, leaving work to keep clinic appointments and the need to travel long distances to the clinic. Twenty eight percent (28%) of the respondents cited distance from the health facility as a barrier to adherence. In Namibia, distance to the ART clinic of the Intermediate Hospital Oshakati is very far from surrounding villages and it poses a threat to ART adherence.

2.5.3 Nature of treatment

According to the adapted net positive perceived pressure models, the nature of the treatment regimen is another factor that can influence adherence. In their meta-analysis to determine predictors of virologic suppression and using twenty three (23) clinical trials involving 3257 patients, Bartlett, Demasi, Quinin, Moxham & Rousseaus (2001:1369) found that pill burden was one of the most significant predictor of antiretroviral response at forty-eight (48) weeks.

A prospective study of predictors of adherence to combination antiretroviral medication was done in North Carolina at a country hospital HIV clinic, between February 1998 and April 1999 (Golin et al 2002:756-765). The study found that dose frequency was related to adherence, although the total number of pills and the total number of antiretrovirals prescribed was not. Frequent dosing was seem to lead to forgetfulness and hence to patients missing doses.

A study done in Brazil from May 2001 to May 2003 by Palmira, Gbele, Fransisco, Maria, Menezes, Juliana, Lorenza, Ricardo and Mark (2005:55-513), confirmed that the number of pills per day was associated with an increased risk of non-adherence. The study's objective was to assess the incidence, magnitude and factors associated with the first episode of non-adherence for twelve (12) months after the first antiretroviral prescription.

Consistent results were reported by Weiser et al (2003:287), where they found that thirty (30%) of patients believed that they had swallowed too many pills every day. Five percent (5%) of the patients stated that the large quantity of pills interfered with their ability to take treatment.

2.5.4 Health workers related factors

Health workers related factors constitute a set of either net negative or net positive perceived pressure on patients' adherence to ART. The way the patients were treated the last time they used the health services could have some influence on their willingness to go back to the same place for service. Clinical studies investigating the effect of the patient-provider relationship on adherence behavior are limited (Machtinger & Bangsberg 2006:14). A qualitative study investigating the effect of the patient-provider relationship on adherence behavior in Brazil by Malta et al (2005:1429) from 2001 to 2002, found that factors that influenced patients' adherence included insufficient time, difficulty with discussing adherence and lack of dialogue about adverse effects.

Physicians had insufficient time to assess patient's needs or concerns that might affect ART adherence because they were overwhelmed with work. Some physicians avoided discussing adherence with their patients because of uncertainty about how to discuss ART adherence. Some physicians did not discuss the potential side effects of ART regimens even before initiating their patients on a new ART regimen. This is in contrast to the clinical Manual (2005:4) which encourages clinicians to work closely with patients and to treat side effects and to consider alternative regimen if necessary.

Increased unnecessary prolonged waiting time at the clinic, long queues and rude, unempathetic staff affect negatively patients adherence whilst patients' overall satisfaction and trust may positively affect adherence to ART.

2.5.5 Social habits and lifestyles

Active alcohol consumption, drug use and unstable housing are associated with poor adherence to ART in America and Western Europe (Clinical Manual 2005:3). In Brazil, Malta et al (2005:1428) recruited forty (40) physicians who were involved in the treatment and care of people living with HIV/AIDS. In-depth interviews were conducted between 2001 and 2002 in which some physicians cited patients' social habits and routines as impacting negatively on adherence. Physicians were of the opinion that improved understanding of an individual patients' lifestyle and guiding development of a regimen to fit the patients' specific needs can increase adherence. The use of alcohol and illicit drugs was found to be associated with non adherence in a study done in Brazil (Palmira et al 2005:55-513). In Namibia alcohol abuse is rampant with many adults in rural areas with nothing to do, find themselves in binge drinking.

2.5.6 Stigmatization

The threat of social stigma may prevent ART patients from disclosing their status. This may serve as a barrier to ART adherence. In a study by Rintamaki, Davis, Skripkauskas, Bennett and Wolf (2006:366) in Chicago, the effect of social concerns on treatment adherence were evaluated. The overall mean age of the participants was 40.1 years. Forty five (45%) percent were African American and 80% were male. People with high stigma concerns were 3.3 times more likely to be non-adherent to their medication regimens than those with low concerns. The CDC ART clinic at Oshakati hospital is a stand alone building and care facility that is specifically for HIV/AIDS patients. This promotes stigmatization as anyone seen visiting the clinic is automatically associated with ART treatment.

2.6 Summary

ART is lifelong therapy and patients are bound to experience pill fatigue. Regular assessment of patients' adherence to therapy for optimal treatment outcomes is necessary. Adherence to ART is important as it has been shown to lead to reduced morbidity and mortality caused by HIV disease, increased immunologic response and the suppression of viral load and hence an improved quality of life of HIV infected people. The biggest concern of non adherence is the emergency of drug resistant strains, the use of complex and expensive regimens, and the rapid progression of HIV to AIDS, and adherence close to 100% is recommended for effective outcomes of ART. Assessment methods for patients' adherence include patients' self-report approaches, biological markers and immunological markers as CD4 and viral load. Net positive perceived pressure model was used to explain the factors that would influence a patient to adhere to treatment.

Chapter 3: Study design and methodology

3. 1 Introduction

The chapter explains the research methodology namely the study design, target group, sample methods, procedure for data collection, data analysis and ethical considerations. The design is a general plan that describes how the research will be conducted. It focuses on the kind of study proposed and its desired result. It begins with a problem, or question, and in the context of the logic of the research, determines what kind of evidence will address the research question adequately (Mouton 2002:56). A descriptive and explorative study was conducted utilizing quantitative methodology.

3.2 Study design

Polit & Hungler (1999) describe a research design as an overall plan for obtaining answers to the questions being studied and a way of handling some difficulties encountered during the research process. Research design refers the outline, plan, or strategy used to investigate the research problem (Christensen, 1985, p155).

3.2.1 Qualitative.

Qualitative research designs are best suited to research that aims to explore and test the perceptions of health behaviors. This study used self designed semi-structured interview schedules. Qualitative research places the emphasis on the lived experience of the participants. This approach encouraged greater openness from participants, which leads to deeper descriptions and yields richer analysis. Qualitative designs allow greater flexibility in data collection, which give space for the participants to give information beyond what is known (Poe & Mays 1995).

Johnson & Christensen (2000) define qualitative research as research relying primarily on collection of qualitative data (non-numerical data, such as words and pictures). Burns & Grove (2001) concur, describing qualitative research as a systematic, interactive, subject approach used to describe life experiences and give them meaning. The researcher used a

qualitative approach in this study based on Burns & Grove's (2001) and Johnson & Christensen's (2000) definitions, and the major characteristics of the qualitative research identified by Polit & Hungler (1999). These characteristics are (1) naturalistic inquiry (2) holistic perspective (3) qualitative data, (4) personal contact and insight (5) empathetic neutrality.

The chosen methodology allowed the researcher to systematically pursue research questions in real life situation of HIV positive patients on ART and treatment supporters' perceptions on ART adherence within Oshana region in particular and in Namibian context in general (Green & Britten,1998).

3.2.2 Exploratory Design

An explorative research study is conducted when little information is available regarding the phenomenon under investigation (Brink, 1996: 209). There is limited understanding about the effects of perceived roles of ART patients, treatment supporters and health care workers (HCWs) in ART adherence in Namibia. Also the perceived factors that affect adherence as seen by ART patients, treatment supporters and HCWs is not well understood. Exploratory research begins with the phenomenon then investigates its true nature, how it manifests itself and what other factors are relevant to it (Polit & Hungler, 1997, p. 20-21). The research evaluated information perceived to be essential so that the objectives of the study could be addressed. Though studies about perceptions of roles in ART adherence and perceived factors that affect adherence have produced valuable information on the phenomenon, it has not been investigated in the Namibian context, where scarce information is available.

3.2.3 Descriptive design

A descriptive design is used to investigate a phenomenon and the manner in which it manifests itself (Polit & Hungler, 1997:21). The researcher sought to describe the perceptions of ART patients, treatment supporters and HCWs on their roles in ART adherence as well as describe the perceived factors that affect adherence. Babbie and

Mouton (2001: 80) explain that the major purpose of scientific study is to describe situations and events.

3.3 Study population

A study population is any defined group that is selected as a subject for research. If a population can be defined, from oxygen molecules in the universe to supercomputers in the world, then it can be subjected to study and analysis (Melville & Goddard, 1996: 29). A study population includes all the members, or units, of a group that can be clearly defined in terms of its distinguishing criteria, whether they are people, objects or events (Uys & Basson, 1991: 86).

In this study the first study population included HIV positive patients on ART at Oshakati CDC clinic. The second study population included treatment supporters within Oshana region where Oshakati ART clinic falls. The third population of this study included all HCWs working at Oshakati ART clinic.

3.4 Sampling

A sample is a group of people or elements that forms part of a study population. Results from a study of the sample allow general observations to be made about the entire population (Melville & Goddard, 1996, p.30). De Vos (2002: 199) defines a sample as a small portion of the total set of the population, and together they comprise the subject of the study. Sampling is the most feasible way of studying large populations, given resource, time and financial limitations. Convenient sampling was used in this study, so as to suit the researcher busy schedule.

3.4.1 Sample size

The sample size used was 9 HIV positive patients on antiretroviral therapy, 11 treatment supporters and 4 health care workers at the ART clinic at Intermediate Hospital Oshakati.

3.5 Pilot study

According to Christen (1985) a pilot study is described as a smaller version of a proposed study to refine methodology. A pilot study was conducted in September 2010 with two ART patients, two treatment supporters and one doctor at ART clinic, in Intermediate Hospital Oshakati. The aim of the pilot was to determine the clarity of the interview schedules, effectiveness of instructions, time required to complete the interviewing process, sequencing of statements and procedure of recording responses. In health workers and treatment supporters' schedules all the statement were found to be clear and useful.

In the participants' schedules some statements were not clear in the pilot test, and those were rephrased or the sequence rearranged.

3.6 Data Collection Method

This study utilized unstructured interview schedules to collect data from ART patients, treatment supporters and health care workers. Unstructured schedules are recommended to be used in qualitative research when one is seeking to learn about people's feelings, thoughts and experiences (Bowling, 2002). In-depth interviews with ART-patients, treatment supporters and health care workers were conducted in a language of their choice, as the researcher is conversant with most of the languages spoken in the region. Particular care had been taken to ensure that the respondents were comfortable and at ease prior to and during the interview. Probing was done to encourage them to talk freely about their perceptions of their roles toward ART adherence (Robson, 1993). The researcher took field notes during the interviews and also tape recorded the whole interviews.

3.7 Data analysis

Data analysis is the process of systematically organizing the interview transcript field notes and other accumulative materials until they are understood in such a way that they address the research question and present the results and create understanding to others (Patton, 1990: 65). Content analysis was used to organize data into themes, categories and

subcategories in order to synthesize valuable information and meaning from the respondents' raw data. The study results from all respondents were consolidated which gave a clear understanding regarding adherence at ART clinic in Intermediate Hospital Oshakati

3.8 Ethical considerations

Conducting research implies the acceptance of responsibilities. A researcher is responsible to fellow researchers, to respondents, to society as a whole and, most importantly, to himself (Melville & Goddard, 1996:113). A high professional standard regarding confidentiality was strictly maintained. De Vos (2002: 64) identifies ethical issues that are of utmost importance for the researcher.

Informed consent was sought from the management staff of the Intermediate Hospital Oshakati, from the health workers at the ART clinic, and from the HIV positive patients selected for the interviews. The researcher assured confidentiality and information stored safely and only accessed for the authorized staff members such as hospital superintendent, nurse manager and the researcher. The research assured that the subjects participated voluntarily. The researcher maintained a non-judgmental attitude towards the participants in the whole process (Bowling 2002).

Chapter 4: Data analysis and presentation

4.1 Introduction

In this chapter, the findings of this research are presented. The demographic data of the participants for this research is presented as well. The researcher came up with two main themes as follows: Patients on ART, treatment supporters and health care workers' perceptions around their roles in the ART adherence; and patients on ART, treatment supporters and health care workers perceptions around factors that influence adherence.

The research used several categories and sub-categories as displayed in table 4.1 and table 4.2. The themes were directed to satisfy the requirements of content analysis. Content analysis requires the researcher to decide on the unit of analysis, which includes words, paragraphs and phrases that are used in the report. In unit analysis, categories group the data for every presentation the development of categories was done to reduce the data into smaller chunks with the aim of facilitating understanding of data.

4.2 Demographic data of the participants

4.2.1 Doctors and nurses

A total of four medical workers were engaged in the study with the split of 2 registered nurses and 2 medical doctors. All of them were stationed at the ART Clinic in IHO. Among them, the least serving staff had worked there for two years and the most seasoned one had worked there for 5 years. On average, these medical workers had worked at the ART Clinic for 3.7 years which is quite a long time such that the researcher could rely on the responses coming from them as medical workers at the ART. Both doctors and one of the nurses fell in the age group 31 to 40 years and one of the nurses was in the age category 20 to 30 years. This is summarised by the table below:

Table 4.1: Health workers demographic data

Gender	Position	Qualification	Duration worked	Total
Male	Doctor	MCHB MCHB, Dip:HIV/AID Mgt, MPH: AAHIVS	3 2	1 1
	Nurse	Registered nurse	2	1
Female	Nurse	Registered nurse	2	1
Total			**Average: 3,7years**	**4**

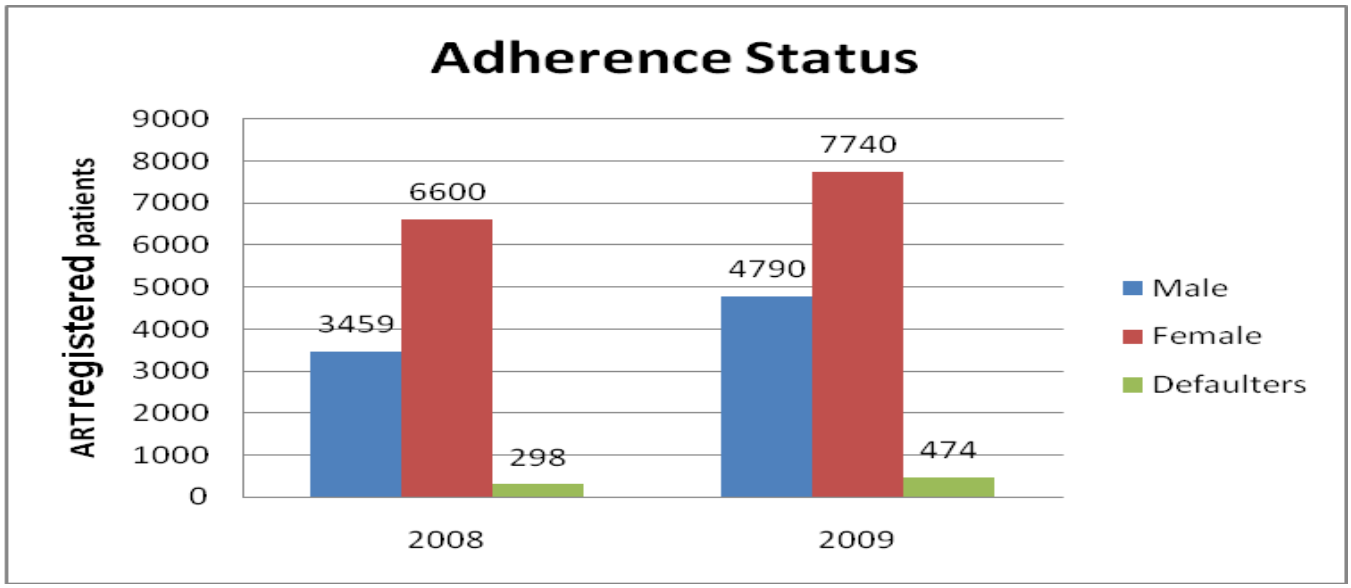
4.3 Patients on ART

Responses were also drawn from 4 male and 5 female HIV positive patients. The youngest among them was 25 years of age and the oldest was 63 years of age. The average age of the patients was found to be 37.1 years. These patients have been on average on the ART for 1.4 years. The patient have been on the programme for the shortest period only had 6 months whist the one who has been there for long had gone for 2 years 1 month under ART.

4.3.1 ART Registered Patients and Adherence Status

The bar chart below shows that in the year 2008 a total of 3459 male and 6600 female ART patients were registered at the ART IHO. There were 298 defaulters that year. In the year 2009, there were 4790 male and 7740 female patients registered. In the same year a total of 474 defaulters were recorded.

Figure 1: Adherence status



It is also evident from the bar chart that for both 2008 and 2009, defaulters were recorded, thus the health workers indicated that they face problems and or difficulties of patients turning up for their follow up. The possible causes why patients would default are listed below according to the order of their importance in the area:

- Lack of transport money thus some patients do not regularly go for follow ups.
- Lack of public transport in some areas.
- Long distances travelling to the Health centre.
- Some employers deny staff permission from work to get to the hospital.
- Stigma in the communities.
- December many default due festive Christmas and weddings.
- During rainy season when most people are busy with cultivation.
- Ignorance: some patient feel better then they default

4.4 Treatment Supporters

Treatment supporters were also engaged in the study. These are the people who were most of the time available to help the patients, be it through the preparation of food, collection of medication, physiological support and many other ways. These patients were sons/ daughters, cousins, niece, nephew, or brothers of the supporters. Of importance, most of them were female and only one supporter was male. This could be because females have the compassion to nurse other people compared to males. All of the supporters engaged in the study were quite mature people as all of them were 30 years or older. The most aged one was 60 years. On average, the patient supporters were aged 42 years. The period for which they have been supporting the patients ranges from 1 year to 7 years. On average, they have been doing this support work for 3.3 years.

4.5 Patient on ART's perceptions around their roles in ART adherence.

The perceptions of patients on ART around current roles in ART adherence, was one of the two main themes that were found in this research. The patients' perceptions around their roles in ART adherence were found to be positive. The main theme as indicated in table 4.2 was further divided into categories and subcategories, which are highlighted in the table. The categories are:

ART patients' about taking medication,
ART patients' perceptions about collection of medicine supply
ART patients' perceptions about diet and medication
ART patients' perceptions about support in ART treatment

Table 4.2 Summary of ART patients' perceptions around their current roles in ART adherence

MAIN THEME	CATEGORY	SUB-CATEGORY	MEANING UNITS
ART patients' perceptions around their roles in ART adherence.	ART patients' perceptions about taking medication daily.	Is a personal responsibility. Done daily the same time. Should not skip doses.	To suppress the HIV virus. To have enough medication in my blood. To avoid resistance.
	ART patients' perceptions about collection of medicine supply and follow up visits.	Must not be missed Where ever you go carry enough supply.	To avoid missing doses which cause resistance. Allow HCWs to review my progress with treatment. Make sure you always have your doses.
	ART patients' perceptions about food and medication.	Must eat before you take medication. You must avoid some foods and alcohol.	To avoid side effects as dizziness. They make the medicine weak.
	ART patients' perceptions about support in ART treatment.	Must have treatment supporters. Must work well with HCWs.	Reminds I on when to take medication and cook food. Give good information on counseling and treatment.

4.5.1 ART patients' perceptions about taking medication daily

From the findings of this research, participants seem to have accepted their responsibility of taking medication daily. This category was further divided into sub-categories: Is a personal responsibility; Done daily and the same time; Should not skip doses.

Other findings of the subcategory are separately presented below.

4.5.1.1. Is a personal responsibility

Most of the ART patients perceived taking medication daily as a personal responsibility. This was because of the realisation of the negative effects of not taking medication consistently as drug resistance and also the benefits of taking the medication consistently as increased CD4 count on follow up visits. The following are the quotations from the semi-in structure questionnaires:

"I take it as my responsibility for life and I feel good for it because there is a health benefit in it."
"I accept it as my responsibility for life to take medicine that rescued me from death, because I was seriously sick."

4.5.1.2 Done daily at the same time

Taking ART medicine daily at the same time was perceived as one of the pillars of effectiveness of ART treatment by ART patients who participate in this study. The reason given included the need to ensure that there is always enough medication in the blood to suppress the HIV virus. The following is an extract from the some of the responses from participants:
"I decided to join the program (ART) in order to drink medicine daily which will suppress the virus down in my blood and I will live longer, do my work as well".

4.5.1.3 Should not skip doses.

Most of the respondents perceived not skipping doses as one of their responsibilities in ART adherence. Some of the respondents stressed that skipping doses would result in resistance to medication. They also expressed that resistance would make their bodies weak or defend themselves and they will be bedridden. This they said would cause them to lose their income and will not be able to feed their children. One of the ART patients interviewed,
"Not skipping doses is good...I feel good that I am health and live longer, to help my children because they are young".

4.5.2 ART patient's perceptions about collection of medication supplies and follow up visit?

From the research findings, participants seemed to have accepted collection of medication supplies and going for follow up as their role in ART adherence. Most of the respondents emphasized that collection of medications and a follow up visit is of paramount importance in ART adherence. They said enough supply of medication ensures that no doses are missed which will ensure maximal viral suppression and eliminating drug resistance. They also expressed the benefits of follow up visits including being able to be clinically and immunologically evaluated by nurses and clinicians. It will also accord them the opportunity to be attended to any other illness as well receive valuable reinforcement counselling. The following are some of the extracts from ART patients interviewed:

"Though in the rain season flooding causes me to walk very long distance to the alternative bus stop...I try to come a day before so I will make time to come for follow up visit and collect my medication!"

4.5.3 ART patient's perceptions about food and medication

Most of the ART patients interviewed perceived eating healthily as one of their roles in ART adherence. All participants reported that they ate before they take their medication. To express the importance of food in ART treatment, some of the respondents even expressed gratitude to relatives who bought or prepared food for them. Some even appealed to government to provide food handouts. Some of the respondents even mentioned some of the adverse drug interactions which they perceived as occurring when they took their medication without food. One of the respondents cited dizziness as one of the effects of not taking food. Some of the quotations from extracts of participants' respondents as follows:

"I eat first after 20 minutes I drink medicine. It helps to prevent dizziness."

"It could be good if government can source an organization that can provide food to patients on ARVs. I am just surviving in my disability grant and my mother's pension to fulfil all our needs including food."

4.5.4 ART patient's perceptions about support in ART treatment.

Having a treatment supporter is one of the qualifying factors in the initiation of patients on ART in Namibia though one can not be denied treatment in the absence of a treatment supporter. Most of the participants interviewed highlighted the importance of sourcing a treatment supporter as one of their perceived roles in ART adherence. Some of the ART patients expressed that it gave them strength to continue in ART when their families accepted them after knowing they were HIV positive. Most of the participants expressed that they created good relations with their close families who in return become their treatment supporters. Some also expressed the good interaction they had with health care workers.

Though a few said they did not want anyone to help them, this study revealed that a treatment supporter is a valuable shoulder to cry on as well as someone to share laughter with. Some expressed that during the first two months of their treatment they experienced bouts of vomiting and diarrhea. They said they felt like stopping treatment, but with the encouragement and counseling of treatment a supporter they continued. Some said they could not walk, so the treatment supporter went to collect medicine and cooked for them. They received psychosocial support from these treatment supporters. These perceptions of psychosocial support are expressed in some of the extracts from some structured interview as follows:

"The relationship with my mother and my sister is still good. They are my support in everything e.g. remind me and cook for me!"

"I had my sister already who is reminding me to take medicine. I need her to prepare food for me also. She is the one that put alarm for me, just to remind!"

"I do not think I need some body now, because I can look after myself. I have a reminder alarm for taking medicine and for follow-up as well."

4.6 Treatment supporters' perceptions around their roles in ART adherence.

Treatment supporters' perceptions around current roles in ART adherence was one of the two main themes that were found in this study. Treatment supporters' perceptions around their roles in ART adherence were found to be positive. Treatment supporters' perceptions around their roles in ART adherence were divided into categories and sub-categories which are highlighted in the table 4.3. The categories are: Treatment supporters' perceptions about follow up visits and

collection of medication and Treatment supporters' perceptions about encouraging personal hygiene.

Table 4.3. Summary of treatment supporter's perceptions around their role in ART adherence.

MAIN THEME	CATEGORY	SUB CATEGORY	MEANING UNITS
Treatment supporters' perceptions around their role in ART adherence	Treatment supporters' perceptions about follow up visits and collection of medicine.	Important huge responsibility. Walking long distance for a purpose.	To ensure adherence health care workers measure our effort and gives us strength.
	Treatment supporters' perceptions about psychosocial and emotional support.	Initially drug reactions are worse. Initially patients are weak and can't walk or work. Recovering can also be deceiving to the patient.	Need someone to encourage them to continue. Need someone to talk to and do the all chores for them. Some may want to fall back to their old habits.
	Treatment supporters' perceptions about giving food and medication.	Too weak to remember to eat. Must take medicine consistently every day.	Eating healthy help medicines to work and limit adverse effects. To minimize drug resistance.
	Treatment supporters' perceptions about encouraging personal hygiene.	HIV patients easily get opportunistic infections.	Personal hygiene minimizes communicable diseases.

The findings of the above categories and their sub-categories are presented below. Quotations in the participants own words have been used to enrich the findings of this research.

4.6.1 Treatment supporters' perceptions about follow up visits and collections of medication.

From the findings of this research participants seem to have accepted their roles in ART adherence. This category was further divided into sub-categories as indicated below:

- Important huge responsibility
- Walking long distance for a purpose

Most of the treatment supporters perceived follow up visits and collection of medication as an important responsibility to maximize ART adherence as they have to make sure their patients attend all follow up visits without failure to minimize dose skipping and hence drug resistance. Treatment supporters perceived the hard task of walking long distances as a purpose driven task. Though they felt the pain of walking long distances, it was evident from their explanations that it was important for their patients to be reviewed by health care workers. Clinical and immunological review of patients was a measure of the success of their efforts. If the patient improved after each follow up visit, it would give them strength to continue. Like one treatment supporter said, it clearly shows that the role of going with patients for follow up is not an easy task as shown below.

"The long distance becomes worse during the rain season. It makes me to carry my son and pass through pools of water, but I notice the improvement of the health condition of my son…I am encouraged to continue to take care and walk + 45 km to reach the ART clinic at Intermediate Hospital Oshakati."

"…We are footing sometimes because of lack of transport money."

"…….feel that to be responsible towards ART adherence..."

4.6.2. Treatment supporter's perceptions about psychosocial and emotional support.

Most of the treatment supporters perceived psychosocial and emotional support as a critical role from initiation of ART, which promote ART adherence. This category was further divided into sub-categories as indicated below:

- Initially drug reactions are worse
- Initially patients are weak and can't walk or work
- Recovering can also be deceiving to the patient.

From the findings of the research, treatment supporters seem to have accepted their role of going for follow up visits and collection of medication. However they perceived it as a challenging task which they have evolved to cope with, with minimum hindrances. Most of the participants echoed that during the initial phases of treatment drug intolerance among patients is very high. A lot of the participants mentioned diarrhea and vomiting, rash, dizziness, headache and joint pain.

These side effects of medication may be so severe that the patient may refuse to take their medication. So those patients without supporters will have a high chance of defaulting. The treatment supporters also revealed how much valuable information they had obtained from formal training on drug interactions and side effects. They reported that at times the side effects are so severe that they had to take the patient to the doctor. The doctors changed medication for patients with severe side effects.

These sentiments are expressed in the following extracts from treatment supporter responses as follows:

"At the initiation of ARV syrup he starts vomiting and diarrhea for 5/12 months, then doctor changed the syrup to tablets, currently he is gaining weight and he is no longer vomiting."

"…The child developed skin rashes at the first month but now it disappeared."

"…First month, the child (13 years) was vomiting and was always complaining that he can not swallow the medicine well."

Most of the treatment supporters reported that at the initiation of ART, most of the patients are too weak to walk or work and as such can not get to the ART clinic on their own. Without a treatment supporter these patients would miss their follow up visits as well as run out of medicines and this would compromise ART adherence.

As one treatment supporter put it in response to the experiences gained as a treatment support,
"…It gave me a burden to take care of her when she was weak initially, even during the night…I took her to the hospital, I feel good because she was sick and could not hear properly before ART treatment but now he is well."

Most of the treatment supporters expressed that when patients start to feel better they are encouraged to continue with treatment, but some become deceived and revert to their old negative habits. These negative patient habits may cause patients to default from their treatment. So treatment supporters perceived their role in psychosocial support as reinforcement of positive behavior to increase ART adherence. This was alluded to by one of the treatment supporters as follows:
"Some of my patients do not adhere to the treatment, or some continue to use alcohol, so I have to try to talk to them…"
Some of the treatment supporters reported that they have to resort to consistently give health education to hence positive behavior on patients showing full signs of recovery.

4.6.3 Treatment supporter's perceptions on giving food and medication on time.

Giving food and medication on time was perceived to be critical role in ART adherence, by most treatment supporters. This category was further divided into sub-categories as indicated below:

- Too weak to remember or eat,
- Must take medication consistently every day.

Almost all treatment supporters reported that preparing food was one of their chief responsibilities, as most of their patients were too weak to do house chores. Most of them reported that eating healthily every day before medication helps minimize drug intolerance. Forgetfulness to take medicine was one of the factors highlighted by treatment supporters as a hindrance to ART adherence. In order to minimize default due to forgetfulness some bought alarm clocks or programmed on their cell phones, the times for taking medication. This they say minimized skipping one of the requirements for taking ART medicine, and if not for treatment supporters, it would not be possible. Some of these sentiments are expressed below:

"...To assist my cousin where needed, remind her to take her medication and her follow-up date in mind, support her psychologically and emotionally if needed."
"…to give medicine at 7H00 and 1900H00...prepare food for the child and lunch pack."

The treatment supporter caring for her nephew had this to say:
"….to gives medicine on time 7h00 and 1900 hours, and if we go on a visit, I carry the medication alone."
"….To give him food in order to take medicine or take food after."
"Give medication…providing spiritual counseling, and to explain why they take medication."

4.6.4 Treatment supporters' perceptions about encouraging personal hygiene.

Ensuring personal hygiene of patients was identified by some of the treatment supporters as a mainstay to prevent communicable diseases to which most HIV positive patients are susceptible. HIV positive patients are prone to opportunistic infections which are easily picked up when personal hygiene is at a minimum.
"…make sure her clothes are clean, the environment…And encourage her to maintain personal hygiene."
"…It is needed to take care of a patient's personal and environmental hygiene."

4.7 Health Care Workers' perceptions around their roles in ART adherence.

Health care workers (HCWs) perceptions around their roles in ART adherence was one of the two main themes that were found in this study. The HCWs perceptions around their roles in ART adherence were found to be positive. The health care worker perceptions around their roles in ART adherence were divided into categories and sub-categories which are highlighted in the table 4.4. The categories are: HCWs perceptions about monitoring patients; HCWs perceptions about pill count in monitoring adherence; and HCWs perceptions about questioning and counseling patients on adherence.

Table 4.4 Summary of Health Care Workers' perceptions around their role in ART adherence.

MAIN THEME	CATEGORY	SUB-CATEGORY	MEANING UNITS
Health Care Workers (HCWs) perceptions around their role in ART adherence	Health Care Workers (HCWs) perceptions about monitoring patients	Clinically Immunologically	Physical response to treatment Viral load suppression by ARVs.
	Health Care Workers (HCWs) perceptions about pill count in monitoring adherence.	Count tablets left in the container. Ask if any doses were missed.	To monitor if all doses were taken. To be on high alert on possibility of default on time.
	Health Care Workers (HCWs) perceptions about counseling patients.	Reinforcing positive behaviors and minimize negative behavior.	To reduce risk of default and minimize adherence.

The findings of the above categories and their sub-categories are presented below. Quotations in the participants own words have been used to enrich the findings of this research.

4.7.1 Health care workers (HCWs) perceptions about monitoring patients.

It was evident from the findings of this research that participants accepted and treasured their role of monitoring patients to ensure ART adherence. This category was further divided into sub-categories: Clinically, and Immunologically.

Most of the Health Care Workers (HCWs) perceived follow up visits as critical, and said they check for patients' weight, health status and presence of opportunistic infections. This they say will enable them to see if the patient is physically responding to treatment. They will also assess for any possible side effects of medication as rash. Most of the HCWs perceptions were that if the patient is not monitored clinically, predictions on possibility of default will be difficult to make on time. This will than bring about drug resistance and minimize adherence. HCWs felt loss of weight or development of opportunistic infections in patients on ARVs always trigger possible dangers of default or resistance. HCWs also reported that they monitored their patients immunologically which involved collection of bloods for viral load, CD4, ALT, Cretonne and Hemoglobin (Hb). The HCWs perceived this as a critical component of their role in ART adherence. Under normal circumstances one would expect CD4 count to go up and viral load to go down in patients on ART, as reported by HCWs. The HCWs reported that if this normal pattern is not observed it will alert them of pending danger of either resistance or default. This they say will help them screen patients who really need much time on adherence counseling. HCWs also reported the challenge of ARV treatment as that of hepatic toxicity of some of the medication. They monitor this by doing ALT and Creatinine test.

Immunological monitoring would include viral resistance test especially in patients who have shown signs of treatment failure. Health care workers said they will then ask for the laboratory to assess the mechanism of resistance as well as the particular medications

involved so as to change medication to effective ones. These sentiments are expressed clearly in some of the quotations below:

"…Do monitoring adherence by ordering laboratory tests as well as viral load to detect poor adherence."

"…We monitor clinically, immunologically e.g. viral load and CD4 cell count."

"…The clinical and immunological picture of the patient tells us a big story behind ART resistance, without it we will be walking in complete darkness."

4.7.2. Health care workers (HCWs) perceptions about pill count in monitoring ART adherence.

It was apparent from the findings of this research that participants accepted their role of pill counting to monitor ART adherence. This category was further divided into sub-categories: Count the tablets left in the container, and ask if any doses were missed

All the Health Care Workers (HCWs) reported that they monitor ART adherence through pill count. Health care workers reported that they do pill counting for the first three months for patients starting the treatment. After six months when the patient show good adherence the Health Care Workers (HCWs) relax pill counting. HCWs reported to do pill counting for each and every patient.

"We do pill counting and see how many pills were given before and how many they come back with, then we tell the difference…"

This role of pill counting to monitor ART adherence was perceived by some HCWs)as a challenge. "Pill dumping" was the most raised concern. HCWs are of the opinion that some patients throw away pills to appear to be more adherent. This limits the reliability of this assessment method. The following were some of the reports.

"A patient can also be clever, then can remove and throw away pills."

"But you know somebody can still throw away the tablets."

Some Health Care Workers (HCWs) therefore think that enquiring from the patient the number of times they take treatment and asking whether they have ever missed treatment

(self-reporting) is helpful. Most HCWs use patients' self reporting as one of the methods to access patients' adherence to ART, and explained that this is done by sitting down with the patient and asking how the patient has been taking medication. If communication skills are good, the HCWs believe that the patient will be free to even include wrongdoings. The following are quotations from HCWs that illustrate the use of patients self reporting.

"And when you sit down with the patient and try to talk to them some admit that they skipped treatment."

"We just talk to them; you know a patient should be free to tell you really the correct thing. You should not be watching over him like a policeman."

Health Care Workers (HCWs) reported some problems associated with self reporting including solely relying on the information from the patients and the fact that patients sometimes do not tell the truth. HCWs)were quoted as saying:

"They tell us they are adherent, they have never missed a pill and we believe."

4.7.3 Health care workers (HCWs) perceptions about counseling patients

It was clear from the research findings, that participants accepted positively their role of counseling patients to ensure ART adherence. This category was further divided into sub-category as follows: Reinforcing positive behavior and minimizing negative behavior.

Most Health Care Workers (HCWs) reported that alcohol interfered with patient's adherence to therapy; their intervention strategy was to advise through counseling patients to change their life styles. The following quotations by HCWs support this strategy:

"We usually encourage them to stop drinking alcohol if drinking alcohol is the problem."

Some of the Health Care Workers (HCWs) reported addressing religious beliefs in some counseling sessions. It was the HCWs opinions that wrong information that patients get from the churches interfered with adherence, and the intervention strategy was to address the pastors from churches.

"We also go to the pastor, we talk to them if they can also teach, if they can give correct information in the churches about HIV/AIDS."

Most of the Health Care Workers (HCWs) identified continuous counseling as one of the intervention strategies that have been proved to help in ART adherence. One health care worker testified that counseling patients each time they come to the clinic has worked.

4.8 ART patients, treatment supporters and health care workers' perceptions on factors affecting ART adherence.

4.8.1 ART patients perceptions on factors affecting ART adherence.

Table 4.5. Factors affecting ART adherence: ART patients

Perceived factors	Frequency
1. Socioeconomic factors	4
2. ART clinic related factors	5
3. Workplace related factors	1
4. Natural calamities	3
5. Patient related	3

It was evident from the findings of this research that ART patients perceived a number of factors as affecting ART adherence as seen in table 4.8 above. A number of ART patients reported socioeconomic factors as a challenge to ART adherence. This included lack of money, transport and poverty, while ART clinic related factors included negative attitudes by ART clinic staff, long distances to the ART clinic, long queues as well as long waiting times as the clinic. Work related factors included being prohibited by supervisors at work to attend follow up visits to the clinic. Natural calamities on the other hand included flooding during the rainy season. Patient related factors included self stigmatization, not being willing to wake up early in the morning so as to travel to the ART clinic, and alcohol abuse. These factors are explained in the following quotations from ART patients interviewed:

"My supervisor does not understand me when I am telling him I am going for follow up, he makes me go the next day just keeping me working."

"…Just a long waiting time in the clinic which make me not to back to work any more."

"…Self stigmatization at the beginning didn't allow me to be seen by some people that I am taking ARVs, this made me not drink my medicine when they are around or I will take them in a hidden place."
"I take also alcohol (traditional brew) which makes me forget and sleep."
"Long queues and bad treatment by ART clinic staff members at pharmacy."

On the other hand treatment supporters had most of their perceived factors (that affect ART adherence) almost similar to those of patients as most of the time they are together. Their experiences and feelings tend to complement each other.

4.8.2 Treatment supporter's perceptions of factors that affect adherence

Table 4.6. Factors that affect adherence: Treatment supporters

Perceived factors	Frequency
1. Long distance and lack of money and transport to ART clinic	6
2. food insecurity	5
3. Adverse drug reactions	6
4. Long queue at ART clinic	6
5. Flooding	3
6. Patients abuse alcohol	1

It is evident from table 4.6 above that treatment supporters perceived socioeconomic issues as money, food and long distances to the ART clinic as a threat to ART adherence. ART clinic factors such as long queues were also mentioned. The other major perceived threat to ART adherence was adverse drug reactions as highlighted on the following quotations from treatment supporters:

"Household food insecurity, long distances especially during the rain season."
"Some of my patients do not adhere to the treatment, or some continue using alcohol…"
"At first month she experienced vomiting and developed skin rash."

4.8.3 Health care workers (HCWs) perceptions on factors affecting ART adherence.

Table 4.7. Factors affecting ART adherence: Health Care Workers (HCWs)

Perceived factors	Frequency
1. Money, transport and distance to ART clinic	4
2. Forgetfulness	1
3. Feeling better	1
4. Adverse drug reactions	2
5. Alcohol abuse	2
6. Stigmatization	1
7. Alternative medication	1
8. Work related	2
9. Lack of trained treatment supporter	2
10. Flooding	1

Socioeconomic factors were also echoed by all Health Care Workers (HCWs) interviewed as by ART patients and treatment supporters. Health Care Workers brought in other dimensions of factors such as lack of trained treatment supporters, and use of alternative medicines, and stressed that patients without trained treatment supporters tend to default treatment more than those with trained treatment supporters as expressed in these extracts from the interview with Health Care Workers (HCWs) as follows:

"A trained treatment supporter and a well counseled ART patient is a formidable force to recognize in ART adherence."

Alternative medicines such as herbs to Chinese medicines were identified by HCWs as a threat to derail ART adherence. Patients are said to be made to believe that immune boosters are good replacement for ARVs. This was well expressed by one health care worker as follows:

“These guys who market these alternative medicines are concerned with their pockets, not the patient, and they know that these patients are desperate and can do anything as long they are promised of a cure.”

The other factor brought in by health care workers was that of patients who when they have fully recovered form their bedridden sickness tend to fall back into past negative behaviors such as unprotected sex with multiple partners, alcohol abuse and end up not coming for follow up visits and then default from treatment. This was reported by one health care worker as follows:

“After taking medication they recover well and soon forget they it is the medicine that make them well and they stop taking them again.”

4.8.4 ART patients, treatment supporters and health care workers (HCWs) perceptions on factors that enhance ART adherence.

All three parties interviewed in this study namely ART patients, treatment supporters and health care workers reported decentralization of ART services to clinics as a need for patients to maximize ART adherence. In places where they are no clinics, they proposed that mobile ART clinics be provided. The socioeconomic challenges which included lack of money, made it difficult for patients travel to Oshakati ART clinic which is very far for most patients. Health care workers and ART patients jointly reported that advocating for HIV/AIDS workplace programmes to educate employees and employers on HIV and ART treatment, is an important strategy to enhance ART adherence. Health care workers and treatment supporters reported that continuous counseling would also have the benefit of reinforcing positive behavior and maximizing ART adherence. Reduction of waiting times at ART clinics was reported by all the parties and further supported by ART patients and treatment supporters who added that ART clinics must increase staff and improve negative attitudes of staff, as this would help in ART adherence. ART patients felt that disclosure of status to families and close friends help gain support and enhance ART adherence.

Table 4.8 Perceived factors that enhance art adherence

PERCEIVED FACTORS THAT ENHENCE ART ADHERENCE	HEATH CARE WORKERS	TREATMENT SUPPORTERS	ART PATIENT
1. Decentralized ART program to clinics	✓	✓	✓
2. Minimizing stigmatization	✓		
3. Mobilization HIV/AIDS workplace programs	✓		✓
4. Continuous counseling	✓	✓	
5. Reducing waiting times at ART clinics	✓	✓	✓
6. Provision of food handouts to ART patients		✓	✓
7. Increase staff and improve negative attitude at ART clinics		✓	✓
8. Disclosure of HIV status to family and friends			✓
9. Financial support		✓	

4.9 Summary

This chapter dealt with the presentation of research findings. The demographic characteristics of participants were presented. Content analysis was used to analyze the data. The two main themes were the "ART patients, treatment supporters and health care workers (HCWs) perceptions around factors affecting ART adherence." Each of these main themes has several categories that were designed to further reduce the data into smaller manageable chunks.

The following chapter is on the discussion, the conclusions and recommendations according to the researcher.

Chapter 5: Discussion, Conclusion and Recommendations

5.1 Introduction

This chapter presents a discussion, the conclusion and recommendations made by the researcher. The discussion draws from the research questions and research objectives. In this discussion, the researcher compares these findings with existing literature related to adherence to ART. Conclusions are drawn from the research findings and recommendations are made.

5.2 Discussion

In this section the main themes and the categories that were developed during data analysis are discussed. This was done in order to meet the research objectives and to make sure that the research questions are answered. The participant's demographic data is discussed. ART patients, treatment supporters, and health care worker perceptions around their role in ART adherence, as well as their perceptions around factors that affect ART adherence are discussed as the two main themes.

5.2.1 The demographic characteristics of participants

The demographic characteristics that were seen to be very useful in this research were the number of years of experience in the provision of antiretroviral drugs to patients in the public sector in Namibia, basic training in HIV/AIDS management, and basic medical degrees or nursing diplomas. The demographic characteristics considered useful in this study included the period for with they have been supporting the patients as well as their age. In the case of patients, it was the period for which they have been taking medication.

The health care workers' experience in managing patients on ART in the public sector allowed them to share their experiences and give their perceptions about their role in ART adherence as well as perceived factors that affect patient adherence. This also made the health care workers resourceful when it came to sharing their recommendations on how to assist patients who have poor adherence to ART. The health care workers were able to

identify factors that they perceived to impede patient adherence to ART and also shared some strategies they used to improve adherence are Oshakati ART clinic.

All of the treatment supporters were above 30 years old and they had on average been treatment supporters for 3.3 years. This gave them enough experience to share their perceptions around their roles in ART adherence. They were also in better position to say more on factors they perceived to affect ART adherence among their patients.

The duration of treatment by patients on ART gave them the necessary experience sought in this study, which enabled them to share their roles in ART adherence as well as their perceptions of factors that make them not to adhere to ART adherence. On average patients interviewed have been on treatment for more than six months.

5.2.2 ART patients' perceptions around their roles in ART adherence

The discussions in this section will include ART patient's perceptions about taking medication daily, about collection of medication supply and follow up visits, about food and medication, and about support in ART treatment.

5.2.2.1 ART patient's perceptions about taking medication daily.

One of the most important things in the delivery of health care is for patients to understand their disease and be well aware of their role in its treatment. It is very encouraging that most patients interviewed in this study seemed to know their disease very well. Most of the patients really understood their role of taking medication as a pillar to ART adherence. This study revealed that most ART patients perceived taking medication as a personal responsibility, that should be done daily at the same time, without skipping any dose to ensure ART adherence.

These findings are further supported by (Van Dyk, 2008), that it is very important to develop strategies to help patients take responsibility for their own treatment, adhere to ART, and maximize the chances of successful treatment.

5.2.2.2 ART patients' perceptions about follow up visits and collection of medication.

This study found that ART patients perceived collection of medication and follow up visits as a very important role that enhances ART adherence. The perception was very positive in this study even though they expressed that it was a challenging task due to some patient and non-patient related factors. In a study done in Botswana on perceptions and beliefs of physicians around ART adherence, it was found that some physicians perceived some patients to be always giving invalid excuses for missing appointments in the name of long distances. However the same study, also like this one, reported that the majority of the patients adhered to the ART by turning up for their follow up (Dzinza, 2007, p. 145). In a study done in Abuja Nigeria, by Mohammed and Sarki (2004:54), long traveling distances to the clinic was claimed to be one of the factors interfering with adherence. Although patients in this study had transport and distance problems, they reported that they had never missed a follow up visit as they perceived going for follow up visit as their responsibility in ART adherence.

5.2.2.3 ART patients' perceptions about food and medication.

Dzinza (2007:154) reported that some patients on ART in Botswana revealed that because of poor financial status, they failed to get proper food, thus adherence to treatment was affected. Hardon, Dvey, Gerrits, Hodgekin, Irunde, and Kgatelwane (2006:30) found that in most parts of Africa shortage of food has been reported as a major reason for non adherence to ARTs as these drugs were said to increase appetite. The importance of food security and nutrition is seen crucial to adherence, and particularly in the early stages of ART. In some cases the view is that people may not even start treatment when they are not sure about the source of food. Once they are on ARTs they begin to respond and their appetite is regained. The clients can feel that the ARVs are medicines for hunger, and if they have no food they do not take them (Zuurmond 2008:5). In this study the ART patients perceived food preparation and taking medication to be critical elements of adherence. Some expressed that they always take food first before medication. A lot of them expressed that at times they have problems in getting food but parents, relatives and friends always support them with food. The ART patients interviewed in this study had clear perceived benefits for taking food with medication which included avoiding dizziness.

5.2.2.4 ART patients' perceptions about support in ART adherence

Successful ART provision thus requires not just medical attention but also long term social and psychological support, including encouraging and monitoring adherence (Beals, Wight, Aneshensel, Murphy & Miller-Martinez 2006:589-596). Ensuring that medications are taken regularly and on time and that appointments for resupply are kept over a prolonged period of time poses a major challenge for persons on ART and thus the need for a support (Hope & Israel 2007:55). On the other hand community-based efforts engaging treatment supporters are a promising approach towards facilitating adherence (Burrage & Demi 2003:52). In this study ART patients' perceptions about support in ART adherence was highly positive, with most patients expressing that they cannot do without treatment supporters. Most of them used the treatment supporters as reminders of medication times and follow up visits; cooking food for them and provision of money and spiritual support. Thus ART patients perceived lobbing for psychosocial support from families, friends and official community based treatment supporters as also their responsibility to ensure they maximize ART adherence. This study also revealed that support be it financial or psychosocial is mostly needed in the first three months of treatment when the patient is very sick, reacting to drugs and still struggling to cope with the HIV status. It is not only ART patients who had different perceptions about their role in ART adherence, but also treatment supporters.

5.2.3 Treatment supporters' perceptions around their roles in ART adherence

Discussions in this section will focus and will include treatment supporters' perceptions about follow up visits and collection of medication; treatment supporters' perceptions about psychosocial and emotional support; treatment supporters' perceptions about giving food and medication; and treatment supporters' perceptions about encouraging personal hygiene.

5.2.3.1 Treatment supporters' perceptions about follow up visits and collection of medicine

Treatment supporters perceived accompanying patients for follow up visits as a hard and huge task. They reported it to be hard because at times they walk long distances because of either transport or money problems. It wad also hard to them as they had to devote a day or

two of their time specifically for follow up visits every month. They perceived their role in follow up visits and collection of medication as a huge responsibility because it was done at least once a month for the entire life time of the patient. They also perceived it as a huge responsibility and purpose driven, which according to treatment supporters' explanations, makes the burden lighter. They also use follow up visits as a measure of success of their combined effort in ART adherence. A patient who shows signs of improvement will reflect positive results for the effort of the treatment supporter and the patient then in turn will boost their morale.

In a study done in Thailand on roles of parent and family members in ART treatment adherence, (population studies centre research report 2009:12), revealed that besides remembering to take medicines on time, adequate adherence also involves getting resupplies on a regular basis and preparing the medicines to be ready to take. In a study on providers' perceptions of adherence of women living with HIV/AIDS in Puerto Rico (Rivero-Mendez, Dawson-Rose & Solis-Bres (2010:232-251), it was found that a high level of perceived family support and having someone to live for is the most essential dimension of Hispanic familism and extremely important in ART adherence. One of the other important roles of treatment supporters revealed by this study was psychosocial support and will be discussed in the following section.

5.2.3.2 Treatment supporters' perceptions about psychosocial and emotional support.

Emotional and spiritual support for people living with HIV (PLHIV) and their loved ones and care partners is an important aspect of positive living. The development of clinical care models must therefore embrace the need for such non-clinical aspects of care and ensure that HIV care is provided using a more holistic, family-centered approach. Psychosocial support groups (PSS) have been used for many years, and provide a form for patients to receive health information, share experiences, and receive mentorship and counseling (Gloser, 2010: 2-12).

Psychosocial support is the process if meeting a person's emotional, social and spiritual needs. All of these are essential elements of positive human development. Psychosocial

support helps to build resiliency, and it supports families to provide for the physical, economic, educational, and social and health needs of patients. Psychosocial support needs to be part of comprehensive programming. It should not be provided as a stand-alone service, and for HIV patients it entails managing and adhering to treatment, disclosure, coping with illness (Glaser 2010: 2-12).

This study found out that most of the treatment supporters perceived their role in psychosocial support as very crucial especially in the initial phases of ART treatment. This, they said was so because, in the initial stages most patients are very sick can't walk or work. The patients also may experience adverse drug reactions, and all these factors they say may lead the patient to default treatment. In these early stages of treatment patients are still struggling to cope emotionally with sickness and HIV status. Treatment supporters emphasized that it was at this moment that their role becomes handy to the patient. Burrage & Demi (2003: 5) found out that community-based efforts engaging treatment supporters are a promising approach towards facilitating adherence.

In this study, treatment supporters were mature and highly self-motivated to help their patient which in most cases was a relative. Their ability to cook, clean and remind on medication and follow up visits and at times staying awake the whole night with a sick patient reveal their commitment to ensure adherence. Saengtienchai & Knodel (2001: 20) also concluded that sustained assistance with treatment adherence on a prolonged and frequent basis is far more practical if a treatment supporter lives with or nearby the person on ART and has strong motivation to help. Patients who have children in particular are likely to have deep-seated motivation to ensure their grown children's well being.

In this study most of the treatment supporters acted as counselors, educators, reminders, accompaniers, and providers in their quest to provide psychosocial support to their patients.

5.2.3.3 Treatment supporters' perceptions on giving food and medication on time.

Hardon et al (2006:30) found in their study that in most parts of Africa, shortage of food has been reported as a major reason for non-adherence. This importance of food and nutrition is

seen as crucial to adherence, and particularly in the early stages of ART. Of interest is, in some cases the view is that people may not even start treatment when they are not sure about the source of food (Zuurmond, 2008:5). In their study on food security as a barrier to sustainable ART adherence in Uganda, Weiser, Tuller, Frongillo, Senkungu Mukkibi and Bangsberg (2010:10), made the following conclusion on food and ART adherence:

- ARVs increased appetite and led to intolerable hunger in the absence of food.
- Side effects of ARVs were exacerbated in the absence of food.
- Participants believed they should skip doses or not start on ARVs at all if they could not afford the added nutritional burden.
- Competing demands between costs of food and medical expenses led people either to default from treatment, or to give up food and wages to get medications.
- While working for food for long days in the fields, participants sometimes forgot medication doses.

This study showed that treatment supporters made sure their patients had food and medications on time. Though challenges of food shortages were reported by many treatment supporters, they made sure their patients ate something before they took their medication. Treatment supporters took it upon themselves to set clocks or alarms as reminders for medication times for their patients, as they identified forgetfulness, as one of the challenges affecting adherence.

In addition to giving food and medication, the treatment supporters in this study reported that they also encourage patients' personal and environment hygiene to minimize risk of contracting opportunistic infections.

5.2.4 Health Care Workers (HCWs) perceptions around their role in ART adherence.

The discussion in this section will include health care workers (HCWs) perceptions about monitoring patients; about pill count in monitoring adherence; about questioning and counseling patients on adherence.

5.2.4.1 Health Care Workers (HCWs) perceptions about monitoring patients.

In one study in Botswana (Dzinza 2007:116), one physician emphasized that assessing adherence is a complex issue but it is unfortunately a very essential component of HIV treatment. This study showed that health care workers (HCWs) at Oshakati ART clinic used clinical and immunologic monitoring to assess the condition and adherence status of their patients, and said that they use clinical monitoring to assess physical response to treatment, which includes things like weight gain, absence of opportunistic infection and looking clinically fit (health). They use immunologic monitoring to assess viral load suppression by ARVs.

In a study in Botswana by Dzinza (2007:152), one physician indicated that sometimes when some patients decide to stop taking drugs this would be rejected by a change in the viral load as it goes high. Most of the health care workers (HCWs) interviewed in this study perceived monitoring their patients a critical role as it gave them the big picture of their treatment effort on the patient. They said a high viral load in a patient on ART would raise the ART failure or default suspicion index. So they perceive this role as critical and should not be skipped on every follow up visit.

However in this study some health care workers (HCWs) expressed concern with credibility of CD4 test results as in some instances CD4 count reports from the laboratory does not tally well with the clinical picture as well as the viral load report. These findings were also reported by Dzinza (2007:152). The researcher found that despite the belief by most physicians that CD4 cell count and viral load help to monitor patients adherence to ART, one physician did not believe in sending blood to the laboratory for assessing patient's adherence to ART. His argument was that poor immunologic or virologic response could be due to poor adherence or other factors other than poor adherence. Pill count can also be used to monitor patient adherence.

5.2.4.2 Health Care Workers (HCWs) perceptions about pill count in monitoring adherence.

Pill count involves counting of the remaining doses of medication in a specified cycle. The return of excess pills provides tangible evidence of non adherence (Machtinge & Bangsberg 2006:16). The problem with this method is that it is time consuming and determining the date the patient commenced the current prescription can be difficult, especially when patients combine all pills in one bottle (Turner 2002: 146).

All the health care workers in this study reported to be doing pill counts. They however also expressed the challenge of time and patient overload specifically for doctors who felt they could not do pill counts for every patient. In such cases health care workers reported to do counting only for those just initiated on treatment. This finding agrees with findings observed by Dzinza (2007:156), in Botswana that the physicians who reported doing pill counting for every patient during interviews were observed to be doing pill counting for every patient during consultations. Those who do not so for every patient, during consultation were observed not to do pill counting for every patient. They were doing pill counting for patients who had just been initiated onto treatment. This study found that health care workers perceived pill counting as a critical sustainable role in ART adherence which should be done at all sot without failure.

5.2.4.3 Health Care Workers perceptions about counseling patients

This study showed that most health care workers felt continuous counseling was an important role in ART adherence as it reinforces positive behaviors and minimize negative behaviors. This they say will in turn reduce risk of default and maximize adherence Health care workers identified use of condoms, eating healthily, not taking alcohol and taking medication every time on time as positive behaviors and so was coming for follow up visits. Health care workers felt it was their duty to reinforce these positive behaviors each time a patient came for follow up visits. In their study on prevalence and determinants of non-adherence to antiretroviral therapy among HIV-positive pregnant women in Nnewi, Nigeria, Igwegbe, Ugboaja and Nwajia ku (2010:243), reported that the knowledge of determinants of non-adherence factors should be properly utilized and addressed during adherence

counseling programs. The adherence counseling programme should also be regular and sustainable for all patients on antiretroviral therapy for its optimal benefits.

5.3 Perceptions on factors that affect ART adherence

The following section will discuss the perceptions of ART patients, treatment supporters as well as health care workers on factors that enhance ART adherence.

This study revealed that all the three categories of respondents (ART patients, treatment supporters and health care workers), perceived the same socioeconomic factors as barriers to ART adherence. Socioeconomic factors identified included lack of money, transport and poverty. This challenge is imminent in Namibia, where the majority of people living in rural areas have little or no sources of income. This is further compounded by the fact that in Northern Namibia where this study was done, very little rainfall is received per year which makes agriculture impossible to undertake.

Weiser (2003:285) cited some of the factors that affect ART adherence in Botswana as travelling long distanced to the ART clinic and lack of money as well as poverty.

In Northern Namibia, there are a lot of flat plains which easily flood, cutting all roads and transport networks. This study revealed that all the three parties interviewed reported flooding as a chief culprit that affects ART adherence. They reported that patients miss their follow up visits as they will not have any means to cross very large pools of water.

ART patients, treatment supporters as well as health care workers perceived that there are patient related factors that affect ART adherence. All the three participant categories agreed that alcohol abuse by patients was hindering ART adherence. In a study done in Botswana, alcohol was perceived by most physicians to be interfering with patients ART adherence (Weiser et al 203:286). Similarly, alcohol consumption was associated with poor adherence to ART in the US and Western Europe (Clinical manual 2005:3).

Some of the patient related factors reported in this study included forgetfulness, feeling better and unwillingness to wake up early. Treatment supporters and health care workers reported adverse drug reactions as a barrier to ART adherence. Dizziness, rushes, vomiting, diarrhea and headache were the most common side effects reported. Also in Botswana, drug side effects were perceived by physicians to be interfering with adherence to ART (Dzinza 2007:1530).

Maisels, Steinberg and Tobias' findings (2001:188) correlate well with these particular research findings in that patients did not continue with treatment in the US because of side effects. In Brazil, the physicians did not even want to discuss much about side effects with their patients (Malta 2005:1428). Amazingly, side effects did not pose a barrier to adherence in 2000 in Botswana from the findings by Weiser et al (2003:287). This could be due to the fact that in 2000 when Weiser et al (2003) carried out the research, ARVs were not free then. It follows that patients would not have wanted to stop taking treatment because of side effects after incurring financial costs. They would rather have to persevere. Stigmatization was another factor reported by health care workers health care workers and ART patients but not reported by treatment supporters. This was not reported by treatment supporters, most likely because stigmatization is normally perceived to come from families and friends or the community at large. Treatment supporters interviewed in this study were mostly relatives of the patients, and thus their involvement in support would have been a clear indication of no stigmatization.

ART patients reported another form of stigmatization which they referred to as self stigmatization. Some ART patients reported that they did not want to be seen by their friends or family that they were on ART medication. This they say sometimes caused them to miss their doses when family or friends visited them and at times failed to go for follow up visits.

Some patients were perceived to hide their status and not seek treatment. Rintamaki et al (2006:366) in Chicago, US found similar results. They found that people with high stigma concerns were 3.3 times more likely to be non-adherent to their medication than those with

low concerns. Health care workers and ART patients interviewed in this study reported work related problems as affecting adherence. Some supervisors and managers were unwilling to release patients to attend follow up visits.

This study showed that ART patients and treatment supporters perceived some ART clinic related factors as affecting an ART adherence. Obviously, health care workers could not have mentioned this as they would have found it difficult to point fingers at themselves. This study revealed that staff attitudes, long queues and distances to the ART clinic as factors contributing to non ART adherence as mentioned by treatment supporters and ART patients. The ART clinic staff was perceived as unfriendly and always yelling at patients, as well as looking frustrated. They saw ART clinic staff as uncaring, very unprofessional, and lacking communication skills. Although numerous factors are relevant for medication adherence, in people with HIV infection, provider-patient interactions seem to be a key determinant of a patient's success in adhering to regimens (Heyer & Ogunbanjo 2006:5-9).

Literature shows that the provider-patient relationship is a key component that can positively influence adherence. A relationship with a provider that is based on trust, consistency, access and continued interaction has been identified as being important to promote and improve adherence (Abel & Painter 2003: 61-69).

This study showed that the provider-patient good relationship is very low or non existent and this could be attributed to the fact that Oshakati ART clinic is understaffed and has too many patients on ART treatment. Thus the staffs are emotionally and physically stressed, which leaves them with little or no time to show empathy. Kgatlwave et al (2005:6) highlighted factors that impact at health facility levels, such as manpower adequacy, knowledge and skills, and availability of treatment guidelines.

This study revealed two important factors that are perceived by health care workers as affecting ART adherence as follows:

- Feeling better or recovery of the patient,
- Use of alternative medication.

In a study on prevalence and determinants of non-adherence to antiretroviral therapy among HIV-positive pregnant women in Nnewi, Nigeria Igwegbe et al (2010:5) found that 16:3% patients reported missing ARV drugs because they were feeling better and they were no need to take ARV drugs.

This study found out that health care workers perceived that some ART patients received wrong information on the use of herbal medicines, nutritional supplements as well as Chinese medicines. Some health care workers perceived that patients were made to believe that these alternative medicines may substitute ART treatment, thereby making some patient default from them treatment.

5.4 Knowledge gaps in ART adherence

This study revealed a lot of shortfalls in knowledge on ART adherence from ART patients, treatment supporters and health care workers. ART patients seemed to lack proper information on food and nutrition in relation to adherence. This may be due to the fact that ART programs in Namibia are perceived and largely implemented as clinical interventions with primary focus on drugs. Other aspects of care, such as the food and nutritional needs of ART clients, are perceived as secondary issues. Food and nutrition components are not adequately addressed within ART programs and are mostly limited to awareness creation through general nutrition education and counseling at individual or support group level. Only recently are some programs starting to assist with food to ART patients. Service providers (HCWs) perceive food and nutrition support for ART clients as vital to enhancing adherence to, and effectiveness of, ART.

This study revealed that most of the health care workers did not have full details on how to monitor ART adherence of their patients, and perceived monitoring ART adherence as a vital role, but were only using pill count, and immunologic and clinical monitoring. Some of these tools for monitoring adherence have proven shortfalls.

Health care workers did not use simple methods as self reporting and assessing appointments. Though self reporting has limitations of that the method solely relies on patient information who sometimes do not always say the truth, it can be of good use especially when good communication skills are applied. Keeping appointments is another simple method of assessing patients' adherence. Those patients who missed appointments are highly suspicious candidates for default.

Some of the shortfalls identified by this study were on factors perceived to be affecting ART adherence. Quite important factors were mentioned by all parties interviewed but some critical ones were never mentioned. Factors as pill overload, drug combinations, education of patients, lack of patient involvement, type of information conveyed by health care workers.

Health care workers and treatment supporters lacked a clear understanding that ART adherence is pivoted on correct information, continuous counseling, positive personal motivation, patient understands of treatment, and patient's satisfaction with health personnel, giving patients hope and encouragement and supportive environments.

The 2005 American guidelines on ART treatment, advises that providing patients with education prior to writing a prescription is important in assuring adherence to ART (Clinical manual 2005:4). Most health care workers interviewed in this study reported use of treatment supporters as a good way to free patients psychologically, besides the support and reminder to take treatment, the patient finds a person to disclose to. The Namibia guidelines on ART advise health care workers to provide appropriate information to family members and the significant others regarding the importance of adherence and solicit their support and involvement. Unfortunately for Oshakati ART clinic, this is not feasible all the time due to work overload, but however, if more community counselors would be tasked with these tasks then enough information may be conveyed to patients.

Managing side effects due to treatment is perceived to help patients adhere to treatment from health care workers experiences. The clinical manual (2005:4) confirms these

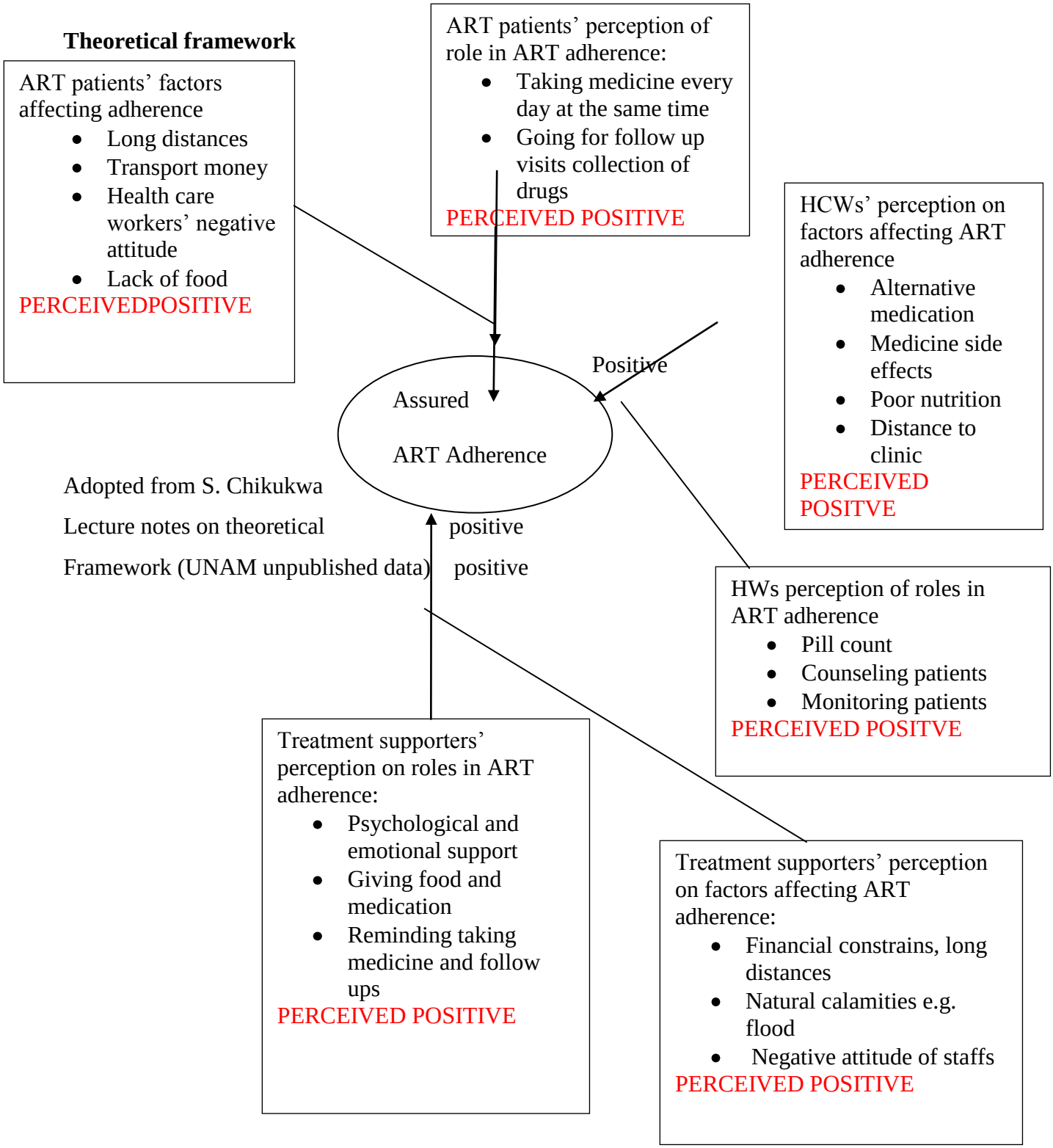
perceptions by advising clinicians to “work closely with the patient to treat adverse effects and consider changes in ART if side effects are not tolerated”. Advising patients about changing lifestyles to suit the treatment regimes has been found to be helpful where alcohol interferes with adherence, patients are encourages to stop taking alcohol.

Community mobilization has been found to help in getting information to the community since poor adherence was also attributed to lack of proper information in the region. Community mobilization also helps in addressing the problem of stigmatization. Some health care workers in this study indicated that since some religious beliefs interfere with patients’ adherence to therapy, some pastors have been approached concerning this.

5.5 Conclusion

Conclusion pre-drawn and given according to the theoretical framework below:

Theoretical framework



As much as all three parties involved seem to understand their perceived roles as well as factors affecting ART adherence, this study revealed they are still knowledge gaps.

As much as the health care workers seem to understand the importance of adherence assessment for the success of ART, it was deduced that assessment of adherence was not consistent among all health care workers. Health care workers did pill counting, clinical and immunologic monitoring on all patients they consulted, but some health care workers appeared a bit relaxed on assessing adherence on for those who had been on treatment for a long time.

This study revealed that staff attitude had a negative effect on patient adherence to ART. Patient-provider relationship is low or non existence, and this is mainly attributed to inadequate staff as well as high volumes of patients.

Disclosure of status is one of the factors that helps maximize ART adherence. None of the parties involved mentioned this, as a factor that affect adherence. This study revealed that use of alternative medicine and feeling affecting ART adherence. Economic factors as lack of transport, money, poverty and distance to the clinic were some of the challenges identified by treatment supporters, ART patients and health care workers interviewed in the study, which negatively affected ART adherence.

Though distance to the clinic was perceived as a challenge by treatment supporter sand ART patients, it was encouraging to note that this study reported that these people were motivated by the benefits ART treatment gives them, and they now take the long distance as an opportunity to prolong life rather than a challenge.

This study revealed that most of the treatment supporters were relatives of the patients and perceived their roles as important. They were seen as the providers, the reminders and the parents who above all gave psychosocial and emotional support to the patients. In this study ART patients were highly motivated and perceived their roles positively and took it as their personal responsibility lifelong commitment. They identified taking medication on time

every day for life as a purpose driven challenge that they see as the only way to be healthy and prolong life.

Overall this study revealed that most of the participants perceived their roles in ART treatment positively and had a good knowledge base of factors affecting adherence. Some gaps in knowledge were identified and solutions are addressed in recommendation section of this study.

5.6 Recommendations

Unannounced pill counts can be developed to curb pill dumping even though this can be intrusive and to some.

To initiate self reporting, and increase its validity by doing a preamble before asking adherence questions. This is to reassure patients that the information will not be held against them and that problems with adherence are nearly universal, so that they tell the truth.

Support nurses should do the pill counting for all patients before they get to the consulting room since doctors seem not to be able to do it routinely most probably because of the time and pressure of work. Adequate manpower should be provided in all departments of ART clinic, to allow proper adherence assessment and continued monitoring and counseling by health care workers.

Health care workers must be provided with customer care training to establish the provider-patient relationship essential for ART adherence. Government should decentralize ART treatment to clinic health centre level to ensure easy access and reduced costs of accessing ART treatment.

There is a need for the conventional medicine to work in collaboration with traditional medicine and religion. Traditional healers, and pastors should be well informed about HIV/AIDS and information communicated to patients should be consistent.

They should be clearly defines on roles of ART patients, treatment supporters and health care workers in ART adherence. There should be a regular training of ART patients, treatment supporters and health care workers on ART and food and nutrition.

5.7 Limitations of Research

The researcher would have liked to take the big but better number of respondents in order to increase different views. But the cost for stationeries, and printing questionnaires were problematic to the researcher.

5. 8 Recommendations for further research

A research study exploring religion and tradition effects on ART adherence is recommended.

Bibliography

Anabwana, G & Jimbo W. (eds), (2005). *Botswana Guidelines on Anti-retroviral treatment* 2005 Version Gaborone: Ministry of Health.

Arnsten, SH. Demas, PA. Farzadegan, H. Grant, RH. Sourevitch, MN. Chang, CJ. Buono, D. Eckholdt, H. Howard, AA and Schoenbaum, EE. (2001). *Antiretroviral therapy adherence and viral suppression in HIV infected drug users*: Comparison of self-report and *electronic monitoring. Clinical infections Disease*, 33: 1417 – 1423.

Babbie, E. & Mouton, J. (2001). *The practice of social research*. Oxford: Oxford University press.

Barlett, J.G (2002). *Pocket Guide to adults HIV/AIDS Treatment*. AETC National

Artlett, JA. De Masi, R. Quinn, J. Moxham, C. and Qousseau, f.(2001). *Overview of the effectiveness of triple combination therapy in antiretroviral – naïve HIV-1 infected adults. AIDS*, 15: 1369-1377.

Beals, KP, Wight, RG, Aneshensel CS, Murphy DA & Miller-Martinez D, (2006). *The role of family caregivers in HIV mediation adherence. AIDS Care* 18(6):589-596.

Brink, H. I. (1996). *Fundamentals of research methodology for health care professionals*. Cape Town: Creda Press

Bowling A (2002). *Research method in health: investigating health and health services*.Second edition: United States of America. Resource Centre. The Johns Hopkins University. [Online], Available: http://baletthiv.com/page68.htm [accessed 7 July 2009].

Burrage, J & Demi A (2003). *Buddy programes for people infected with HIV. Journal of the Association of nurses in AIDS care* 14(1):52-62.

Castro, A, 2005. *Adherence to Antiretroviral Therapy: Merging the clinical and social course of AIDS*. PLOS medicine Journal. 2(12) e 338.

Clinical manual for management of the HIV infected adult. (2005). *antiretroviral Therapy Adherence.* Chapter 3. file://f:/ART. adherence/ARV search 5/getc.htm downloaded 04/02/2011.

Christen, L.B (1985). *Experimental Methodology*., Republic of South Africa, University of Stellen Bosch

De Vos, A. S. (2002). *Research at grassroots.* 2nd edition. Pretoria: J L van Schaik.

De Vos, AS and Fouche, CB (2000). *General introduction to research design, data collection methods and data analysis in Research at grass roots*: A primer for caring professions, edited by De Vos, AS. Pretoria: Van Schaik.

Dzinza 1 (2007). *Perceptions and beliefs of physicians about adherence to anti-retroviral treatment by patients in the South-East, District of Botswana*. Masters degree Thesis: Unisa

Glaser E, (2010). *Strategies for integrating psychosocial support interventions into HIV prevention, care, and treatment services*. Elizabeth Glaser Pediatric AIDS foundation issue brief.

Golin, CE. Lin, H Hays, RD. Milter, LG. Beck, CK. Ickovics J. Kaplan, AH and Wenger, NS (2002). *A prospective study of predictors of adherence to combination anti-retroviral medication.* Journal of general internal medicine, 17 (10): 756-765.

Hardon A, Dvey S, Gerrits T, Hoolkin C, Irunde H, Kgatelwane J, (2006), *from access to adherence, the challenges of ART:* studies from Botswana, Tnzania and Uganda…WHO.

Harmes, Ad. Nyangulu, DS. Hargreaves, NS (2001). *Preventing antiretroviral anarchy in sub-Saharah Africa*, Lamet, 358: 410-414.

Hogan, T. Palmer, C. (2005). *Information preferences and practices among people living with HIV/AIDS: results from a nationwide survey*. Journal of medical library Association, 93 (4):431-439.

Hope, R & Israel E, (2007). *The essentials of antiretroviral therapy for health care and program managers.* Pathfunder international, Technical Guidance series number 5. watertown MA: Pathfinder international.

Kennedy S, Goggin K and Nollen N (2004).*Adherence to HIV Medication: utility of the Theory of self-determination. Cognitve Therapy and research*,vol.28,no.5,October 2004.http://www.springerlink.com/idex/w639JGMUM118755.pdf.[accessed on 7/7/09].

Machtinger, EL. And Bangsberg, DR.(2005). *Adherence to HIV antiretroviral therapy. HIV insite knowledge Base Chapter*. File://f:/ART adherence/insite.hmt downloaded 04/02/2011

Maisels, L. Steinberg, J. and Tobias, C. (2001). *And investigation of why eligible patients do not receive HAART. AIDS patient care and STDs*, 15(4):185-191

Malta, M. Peterson, ML. Clair S. Freitas, F. and Bastos, FL. (2005). *Adherence to antiretroviral therapy study with physicians* from Rio de Janeiro, Brazil. Cad. Saude Publica, Rio de Janeiro. 21(5):1424-1432.

Melville, S. & Goddard, W. (1996). *Research methodology, an introduction for science & engineering students.* Cape Town: Creda Press.

Ministry of Health and Social Services. (2007). *National guideline for antiretroviral therapy*. Republic of Namibia (second edition). Windhoek.

Ministry of Health and Social Services. (2008) *ART Adherence Counseling Training for Health care Workers*. Republic of Namibia, Windhoek

Ministry of Health and Social Services. (2008) *Integrated management of Adolescent and Adult Illness. Comprehensive HIV Care with ART*. Republic of Namibia, Windhoek

Ministry of Health and Social Services (2008). Report of Windhoek 2008 *National HIV Sentinel Survey*. Republic of Namibia, Windhoek

Mohammed, MDd Sarki, R (2004). *Adherence to ART drugs in North-Central zone in Nigeria*. The East and Central African journal of pharmaceuntical sciences, 7(3):52-55.

Murri, R. Amonassari, A. Trotta, MP. De luca, A. Melzi's and Wu, AW (2004).. *Patient-reported and Physician-estimated adherence to HAART*. Journal of general internal medicine, 19:1104-1110.

Nieuwkerk, PT. Sprangers, MAG. Burger, DM. Hoetelmans, RMW. Kauffman, RH and Lange, JM (2001). *Limited patient adherence to highly active antiretroviral thereapy for HIV-1 infection in an observational cohort study*. Arch internal medicine 161:1962-1968.

Palmira, de F.B. Gbele, C. Francisco, A. Maria, C. Menezes, CA. Juliana, A. Lorenza, NC. Ricardo, AC and Mark, DC. (2005). *Non-adherence among patients initiating antiretroviral therapy:* a challenge for health professionals in Brazil. AIDS: 19(4):55-513.

Paterson, DL. Swindells, S. Motir,J. Brester, M. Vergis, EN. Squier, C. and Signh N.(2000). *Adherence to Protease inhibitor Therapy and outcomes in patients with HIV infection.* Annals internal medicine, 133(1):21-30.

Polit, D.F, & Hungler, B.P. (1997). *Nursing research, principles and methods.* (5^{th} ed.). London: J.B. Lippincott Company

Pope,C.Z & S.N. Mays,(2002). *Analyzing qualitative data*: British Medical, 320:114-116[online], Available: *http://www.buy.com/c91/content/full/320/7228/114*[7 July 2009].

Proctor V.E, Tesfa A & Tompkins D.C (1999). *Barriers to adherence to highly active antiretroviral therapy as expressed by people living with HIV/AIDS. AIDS-patient-care-STD's*.1999 Sep; 13(9):535-44 *http://ods.odnih.gov/Health Information/TBIDS*[accessed 5 July].

Rivero-Mendez, M, Dawson-Rose, CS, & Solis-Baezi, SS (2010). *A qualitative study of provider's perceptions of adherence of women living HIV/AIDS in Puerto Rico*. The Qualitative report 15(2) March 2010:232-251.

Rintamaki, LS. Davis, TC. Skripkaiskas, S. Bennett CL and Wolf, MS. (2006). *Social stigma concerns and HIV medication adherence.* AIDS patient care and STD, 20(5):359-368.

Robson C (1993). Ch9-*interview and questionnaire in Robson C really world Research.* Blackwell, 227-243

Shelton R. et al (2006). "*Role of the HIV/AIDS case manager. Analysis of case management, adherence training and co-ordination program in North Carolina. AIDS patients care and STD's"*. March 2006, 20(3):193-204, doi: 10. 1089/apc.2006.20.193. *http//support.libertpub.com[accessed 5 July 2009]*

Turner, BJ. 2002. *Adherence to antiretroviral therapy by human immonodefiency virus infected patients. The journal of infections disease,* 185 supplement 2:5143-5151.

Uys, H. H. M. & Basson, A. A. (1991). *Research methodology in Nursing*. Pretoria: Kagiso Tertiary.

Van Dyk A.C (2008). *HIV/AIDS care and counseling* 4th edition; South Africa. Ceri Prenter publisher.

Vardavas, R. and Blower, S. 2—5. *The WHO Survellance threshold and the emergence of drug resistant HIV strain in Botswana downloaded* 04/02/2011 WHO website.

Weiser, S. Wolfe, W. Bangsberg, D. Thior, I. Gibbert, P. Makhema, J. Kehaabetewe, P. Dickenson, D. Mompati, K. Essex, M, and Marlink R.(2003). *Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana*. Journal of Acquired Immune Devocoency Syndrome, 34(3):281-288.

Zuurmand Maria, (2008). *Adherence to ARVs-challenges and successful.* United Kingdom: CAFOD publication

UNAIDS & WHO. (2007) *Report on global AIDS epidemic. Executive summary*, Geneva: Switzerland.

.

APPENDIXES

Appendix A: Interview schedule 1

Self designed interview schedules which is used to interview the respondents (Treatment supporters

Appendix B: Interview schedule 2

Self designed interview schedules which are used to interview the respondents (HIV positive patients on ART.

Appendix C: Interview schedule 3

Self designed interview schedules which are used to interview the respondents (Doctors and Nurses).

Appendix D

I wrote a letter to the Permanent Secretary for the Ministry of Health Social Services, for the requisition for approval of the research study and it is obtained.

Appendix E:

Permission letter got from the Permanent Secretary of the Ministry of Health and Social Services, for the researcher to conduct a study at ART clinic in the Intermediate Hospital Oshakati and submitted to the senior superintendent of the hospital.

Appendix F: Request for permission from superintendent of Intermediate Hospital Oshakati to conduct a research.

Appendix G: Permission from the Medical Superintendent of IHO to conduct a research.

Appendix H: Preliminary work plan

Appendix A: Interview schedule 1

Name of Enumerator: Ms Olivia Ningeninawa Tuhadeleni
Name of Supervisor: Mr. Gary Eva
Health district: Oshakati Health District
Name of Faculty: ART Clinic in Intermediate Hospital Oshakati
Region: Oshana Region

My name is Olivia N Tuhadeleni; I am currently studying at the university of Stellen Bosch undertaking master in Philosophy of HIV/AIDS management (MPHIL). One of the requirements to be awarded with this degree is to conduct a mini thesis in my area of interest. I have chosen to conduct a research assessing the perceptions of HIV positive patients on ART at ART clinic, intermediate hospital Oshakati, Oshana region.

I would like to ask for some of your time to answer the questions below. All the information obtained will remain strictly confidential and your answer will never be identified. I would like to use the results of this study when planning for training for health workers so that they may offer relevant counseling and education on HIV positive patients on ART and the treatment supporters. The training will also help them in doing proper ART adherence monitoring and evaluation.

The following are the semi-structured interview schedule for **ART treatment supporters** at ART clinic in Intermediate hospital Oshakati (IHO), Oshana region.

1. How old are you? _____
2. Sex (M/F):_____
3. How long have you been an ART treatment supporter? _____

_____

_____

4. What is the relationship between you and the patient you attend?

_____

_____

_____

5. What is your current role as a treatment supporter?

_____

_____

_____

_____

_____

_____

_____

___

6. What is your experience since you started to be a treatment supporter?

_____

_____

_____

_____

_____

7. How do you feel about your responsibility towards ART adherence?

_____

_____

_____

_____

_____

8. How do you experience coming for follow-up visits at clinic on regular basis

_____

_____

_____

_____

_____

9. Is there anything/factors that make it difficult for you to fulfill your role as ART treatment

   supporter?

   _____

   _____

   _____

   _____

   _____

   _____

   _____

   _____

   _____

   _____

   _____

10. Give possible strategies that can be used in order to enhance ART adherence

    _____

    _____

    _____

    _____

    _____

    _____

    _____

    _____

    _____

Appendix B: Interview schedule 2

The perceptions assessment of the of the HIV positive patients on treatment at ART clinic in the Intermediate Hospital Oshakati.

Name of Enumerator: Ms Olivia Ningeninawa Tuhadeleni
Name of Supervisor: Mr. Gary Eva
Health district: Oshakati Health District
Name of Faculty: CDC Clinic in Intermediate Hospital Oshakati
Region: Oshana Region

My name is Olivia N Tuhadeleni; I am currently studying at the university of Stellen Bosch undertaking master in Philosophy of HIV/AIDS management (MPHIL). One of the requirements to be awarded with this degree is to conduct a mini thesis in my area of interest. I have chosen to conduct a research assessing the perceptions of HIV positive patients on ART at ART clinic, intermediate hospital Oshakati, Oshana region.

I would like to ask for some of your time to answer the questions below. All the information obtained will remain strictly confidential and your answer will never be identified. I would like to use the results of this study when planning for training for health workers so that they may offer relevant counseling and education on HIV positive patients on ART and the treatment supporters. The training will also help them in doing proper ART adherence monitoring and evaluation.

I would like you to feel free to participate in the research. For you to ensure confidentiality, be assured that your name will not be revealed in this discussion.

Begin the interview if permission is granted.

Demographic Data

1. Which constituency are you coming from?

   _____

2. How old are you? _____

3. Sex(M/F):_____

4. Could you please tell me about your experience of being on ART?

   4.1 How long are you on ART?_____

   4.2 How did you feel it at first?_____
   _____
   _____
   _____
   _____
   _____

   4.3 What made you decide to go on the program of ART?

   _____
   _____
   _____
   _____
   _____

   4.4 How do you feel about the task of taking medicine every day?

   _____

_____

_____

_____

_____

_____

4.5 What is your current role as a patient on ART?

_____

_____

_____

_____

_____

_____

_____

5. Does your family know that you are on ART?----------
   Yes or No

   5.1 How does your family treat you after they learn that you are on medicine?

   _____

   _____

   _____

   _____

   5.2 Do you take your medicine with food or not? Yes or No.

   _____

   _____

   _____

   5.3 How do you feel after you take the medicine?

Motivate your answer_____

_____

_____

_____

5.4 Is there anybody to remind you on taking medicine?

_____

_____

_____

5.5 Do you take your medicine according to your prescription? Yes/No_____ if Yes what is encouraging you to take medicine regular according to the prescription? If no why are you not taking medicine?

_____

_____

_____

_____

6. What is your experience about coming for follow-up at ART clinic?

6.1 How do you feel about your follow up visit?

_____

_____

_____

6.2 What is encouraging you to stick your follow up?

_____

_____

_____

6.3 Is there anything that makes you not come for follow up? Yes or No_____ if Yes explain:

_____

_____

_____

_____

6.4 If working

How does being on treatment affect your work?

_____

_____

_____

_____

_____

7. How do you perceive the responsibility of taking medicine everyday for life?

_____

_____

_____

_____

_____

_____

8. Do you think you need somebody to be responsible for take medicine? Yes or NO

_____

8.1 If yes, in which capacity?

_____

_____

_____

_____

_____

_____

_____

_

9. Is there anything that influences/hinders your adherence to medicine and follows up?

---

10. Do you thing there is something needed to be done in order to promote or strengthen you to keep on taking ART regularly?

_____
_____
_____
_____
_____
_____
_____

APPENDIX C: interview schedule 3

Semi structured schedule for doctors and nurses at art clinic, Intermediate

Hospital Oshakati: Assessment of perceptions of doctors and nurses at ART adherence at ART clinic,

Name of Enumerator: Ms Olivia Tuhadeleni

Name of Supervisor: Mr. Gary Eva

Health District : Oshakati Health District

Name of Faculty : ART clinic in Intermediate Hospital Oshakati

Region : Oshana region

My name is Olivia N Tuhadeleni; I am currently studying at the university of Stellen Bosch undertaking master in Philosophy of HIV/AIDS management (MPHIL). One of the requirements to be awarded with this degree is to conduct a mini thesis in my area of interest. I have chosen to conduct a research assessing the perceptions of HIV positive patients on ART at ART clinic, intermediate hospital Oshakati, Oshana region.

I would like to ask for some of your time to answer the questions below. All the information obtained will remain strictly confidential and your answer will never be identified. I would like to use the results of this study when planning for training for health workers so that they may offer relevant counseling and education on HIV positive patients on ART and the treatment supporters. The training will also help them in doing proper ART adherence monitoring and evaluation.

Participation is voluntarily, so feel free to participate. I would like you to sign the form for consent of participation in the research, where you are expected to choose the pseudonyms or invented names that will be used during this study in order to emphasize confidentiality..

Demographic Data

Name of the respondent: ----------

Age (Tick the relevant) **between the age of 20 t0 30 years, 31 to 40 years; 45 and above**

Sex----------

Qualification---------- -

Duty station----------

Duration worked at ART clinic: ----------

1(a). How many HIV positive patients registered for ART regimen at your clinic the calendar year of 2008? Fill in by gender: Female: Male: ----------

Total patient defaulted: Female: ---------- Male: ----------

(b) How many HIV positive patients registered for ART regimen at your clinic the calendar year of 2009? Fill in by gender: Female: Male: ----------

Total patient defaulted: Female: ---------- Male: ----------

For 2009: Women----------: Men

Total patients on ART regimen in 2009:----------

Total of patients defaulted ART regimen:----------Percentage (%)----------

2. Do you experience defaulters or difficulties of patients to turn up for their follow-up? Yes or No

If yes, at what seasonal time and why? Explain the possible causes----------

---

---

3. How do you understand ART adherence?

---

4. Do you experience poor ART adherence at your Clinic? If yes explain the possible causes?

---

5. What is your current role towards ART adherence (How do you monitor HIV positive patients on AR?)

---

6. What do you think can be done to improve poor ART adherence among HIV positive patients on treatment in our community?

Appendix D: Request for a permission from Permanent Secretary of MoHSS to conduct a research study at ART clinic in the IHO

P.O. Box 746
Oshakati
28. 10.2009

The Permanent Secretary of Ministry of Health and Social Services

Private Bag 13198
Windhoek

Dear Sir

Re: Study – The request to conduct a research on the perceptions of HIV positive patients on ART and treatment supporters with regard to their role towards RT adherence, at ART clinic in the Intermediate Hospital Oshakati

I am currently registered with the Stellenbosch University in South Africa, undertaking my final year of the **Master Degree in Philosophy of HIV/AIDS Management.** One of my requirements to be awarded with the above mentioned degree is to conduct a **mini thesis pertaining to HIV/AIDS management issue.**

I am a hospital in-service training staff at Nursing Care Quality Improvement but currently acting as a pre-service Tutor at Oshakati Regional Health Training Centre in Pre-severe division.

Namibia is one of the Southern African countries that are threatened by HIV/AIDS; non adherence on medicine including ART is experienced in the world including Namibia. This will results in drug resistance and disease progression with more chances of opportunistic infections. This will have bad consequences on the Government, individual, families, and

the entire community at large. I therefore choose to conduct a study in this regard. The study will be based on the perceptions of HIV positive patients and treatment supporters with regard to their role towards ART adherence.

The findings of this study will provide an insight on how the patients and treatment supporters view their roles towards ART adherence. This could be useful in monitoring and evaluation of HIV positive patients on ART regimen.

Based on the information above I therefore apply for a permission to conduct this study at Communicable Disease Clinic at Intermediate Hospital Oshakati as from the 18 of January 2010.

I thank you in advance

Ms Olivia Ningeninawa Tuhadeleni

Appendix E: Permission letter got from the Permanent Secretary of the Ministry of Health and Social Services, for the researcher to conduct a Research Study.

See scanned documents on the attachment

Appendix F: Request for permission from Superintendent of Intermediate Hospital Oshakati to conduct a study

P.O. Box 746
Oshakati
7 January 2010

The Senior Superintendent
Intermediate Hospital Oshakati
P/B 5501
Oshakati

Dear Sir

Re: Study – The request to conduct a research on the perceptions of HIV positive patients on ART and treatment supporters with regard to their role towards RT adherence, at ART clinic in the Intermediate Hospital Oshakati

I am currently registered with the Stellenbosch University in South Africa, undertaking my final year of the **Master Degree in Philosophy of HIV/AIDS Management.** One of my requirements to be awarded with the above mentioned degree is to conduct a mini thesis pertaining to HIV/AIDS management issue.

I am a pre-service lecturer for enrolled nurses Oshakati Regional Health Training Centre as from

Namibia is one of the Southern African countries that are threatened by HIV/AIDS; non adherence on medicine including ART is experienced in the world including Namibia. This will results in drug resistance and disease progression with more chances of opportunistic infections. This will have bad consequences on the Government, individual, families, and the entire community at large.

I therefore choose to conduct a study in this regard. The study will be based on the perceptions of HIV positive patients and treatment supporters with regard to their role towards ART adherence.

The findings of this study will provide an insight on how the patients and treatment supporters view their roles towards ART adherence. This could be useful in monitoring and evaluation of HIV positive patients on ART regimen.

Based on the information above I therefore apply for a permission to conduct this study at Communicable Disease Clinic at Intermediate Hospital Oshakati as from the 18 of January 2010. Attached please find the permission letter from the Permanent Secretary of the Ministry of Heath and Social Services.

I thank you in advance

Ms Olivia Ningeninawa Tuhadeleni

Appendix G: Permission from Medical Superintendent of IHO

See scanned document on the attachment

Appendix H

Preliminary work plan 2010 - 2011

Activities	**April 2010**	**May 2010**	**June 2010**	**July2010**	**Aug 2010**	**Sept 2010**	**Oct 2010**	**Nov 2010**	**Dec 2010**	**Jan 2011**	**Feb 2011**
Submission of a draft research proposal to	X										
Submission of research proposal to the study leader		X									
Developing research tools			X								
Incorporation of final research proposal						X					
Seeking permission from MOHSS			X (from PS			X (Med-Sup.					
Submission of research proposal and research tools for correction to Mr. Burt Davis							X				

Submission of final research proposal, research tools, permission s to study leader						X	X				
Collecting data								X			
Analyze data									X		
Report writing									X	X	
Submission of first draft report										X	
Incorporation of comments										X	
Submission of final report to Study leader and MOHSS											X